

## Standing frames for children with cerebral palsy: a mixed-methods feasibility study

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**National Institute for  
Health Research**



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# Abstract

## Standing frames for children with cerebral palsy: a mixed-methods feasibility study

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**Background:** Standing frames are recommended as part of postural management for young people with cerebral palsy (CP) Gross Motor Function Classification System (GMFCS) level IV or V. They may have a variety of benefits, including improving bone mineral density, gastrointestinal function and social participation. The NHS needs to know if these benefits are real, given the cost implications of use and the reported negative effects (e.g. pain). The lack of evidence for the clinical effectiveness of standing frames demonstrates the need for evaluative research.

**Objective(s):** The aim of the study was to explore the acceptability of a future trial to determine the clinical effectiveness of standing frames.

**Design:** A sequential mixed-methods design was used. The findings of each stage informed the next stage. We conducted surveys, focus groups and in-depth interviews.

**Participants:** Professionals who work with young people who use standing frames and parents who have a child who uses a standing frame took part in a survey of current standing frame practice ( $n = 551$ ), a series of focus groups (seven focus groups, 49 participants in total) and a survey of research trial acceptability and feasibility ( $n = 585$ ). Twelve young people who use a standing frame were interviewed.

**Results:** Standing frames were widely used as part of postural management for young people with CP both in school and at home but more frequently in school, and particularly by young people in primary school. Achieving the prescribed use was not always possible owing to resources, environment and family factors. Participation and activity engagement were important to young people. The majority of participants believed that standing frames research is necessary. Some reported concern that stopping standing frame use for a trial would cause irreversible damage. The maximum amount of time most health professionals and parents would agree to suspend standing frame use would be 12 weeks.

**Limitations:** Owing to the nature of recruitment, we could not calculate response rates or determine non-response bias. Therefore, participants may not be representative of all standing frame users.

**Conclusions:** Although parents and professionals who engaged in the qualitative aspect of this research and stakeholders who took part in the design workshops appreciated the lack of clinical evidence, our surveys, qualitative information and PPI demonstrated that most people had strong beliefs regarding the clinical effectiveness of standing frames. However, with key stakeholder engagement and careful planning, a trial would be acceptable.

**Future work:** We recommend a carefully planned trial that includes a pilot phase. The trial should evaluate the following question: 'does using a standing frame in school improve patient-reported outcomes of participation (primary outcome), quality of life, subjective well-being, body function and body structure (secondary outcomes) in young children (aged 4–11 years) with CP GMFCS III–V?'.

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# List of supplementary material

## Report Supplementary Material 1 Minutes from design workshops

Supplementary material can be found on the NIHR Journals Library report project page ([www.journalslibrary.nihr.ac.uk/programmes/hta/1314401/#/documentation](http://www.journalslibrary.nihr.ac.uk/programmes/hta/1314401/#/documentation)).

Supplementary material has been provided by the authors to support the report and any files provided at submission will have been seen by peer reviewers, but not extensively reviewed. Any supplementary material provided at a later stage in the process may not have been peer reviewed.





# Glossary

**Activity** The execution of a task or action by an individual.

**Body function** The physiological functions of body systems (including psychological functions).

**Body structure** Anatomical parts of the body such as organs, limbs and their components.

**Children and young people** Children and young people aged 0–19 years with cerebral palsy. Throughout the report, children and young people are referred to as young people unless referring to the young people in relation to their parents; for example, ‘children of the parent respondents’.

**Classroom support assistant** An individual who supports a teacher in the classroom setting by helping disabled young people with their learning through one-on-one support or in small groups.

**Emotional equipoise** A state of genuine uncertainty regarding the clinical effectiveness of standing frames based on an individual’s personal beliefs and feelings (e.g. parents’ experience of their child standing).

**Environmental factors** External influences on functioning and disability. That is, the physical, social and attitudinal environment in which people live and conduct their lives.

**Evidential equipoise** A state of genuine uncertainty about the clinical effectiveness of standing frames based on an individual’s knowledge of the research literature (e.g. conflicting results, weak evidence base).

**International Classification of Functioning, Disability and Health: Children and Youth version** A framework that encompasses functions and structures of the body, activity, participation, personal factors and environmental factors. We have used it to examine the impact of standing frames on a young person’s health-related functioning.

**Participation** Involvement in a life situation (as per the International Classification of Functioning, Disability and Health: Children and Youth version).

**Patient-reported outcomes** For the purposes of our report, patient-reported outcomes refers to quality of life, participation and subjective well-being.

**Personal factors** Internal influences on functioning and disability, that is, individual attributes of the person.



# List of abbreviations

|        |  |        |  |
|--------|--|--------|--|
| BMD    | bone mineral density   | NIHR   | National Institute for Health Research                         |
| CP     | cerebral palsy   |        |  |
| GMFCS  | Gross Motor Function Classification System   | PICOTS | population, intervention, comparison, outcome, timing, setting |
| HTA    | Health Technology Assessment   | PPI    | patient and public involvement                                 |
| ICF-CY | International Classification of Functioning, Disability and Health: Children and Youth Version | RAG    | Research Advisory Group  |
|        |  | RCT    | randomised controlled trial                                    |
| NICE   | National Institute for Health and Care Excellence  | VOCA   | voice output communication aid                                 |
|        |  | WHO    | World Health Organization                                      |



## Plain English summary

Standing frames help people with cerebral palsy (CP) to stand when they cannot do this by themselves. They may also be useful for improving body position, digestion, bone strength and helping young people to join in with others. However, there is very little scientific evidence (or proof) that they are helpful.

Standing frames are expensive and can be painful to use. The NHS wants to find out if standing frames really work. This study aimed to work out if people would take part in a research trial to find this out. We interviewed young people with CP and asked parents and professionals who work with young people with CP (who use a standing frame) to answer questions in surveys. We also asked parents and professionals to take part in focus groups.

We found that lots of things make using a standing frame difficult, such as a lack of time, space or support. Young people want their standing frames to help them take part in things. Some parents and professionals, such as physiotherapists, think that it is dangerous to stop using a standing frame for a long time but may stop for a short time for a research trial.

The people who took part in the study believe that standing frames help in lots of different ways, although most think that more research is needed.

This study shows that in a future trial the most important things to find out are:

- Does using a standing frame help a young person to feel more satisfied, healthier or happier?
- Do they make it easier for them to take part in activities?
- Can they help with body functions (like breathing and digestion) and body structure (like bones and muscles)?

A research trial needs to be carefully planned to help people to take part.



# Scientific summary

## Background

Cerebral palsy (CP) is the most common motor disorder of childhood, affecting 1 in 400 children. CP is associated with abnormalities of muscle tone and posture with secondary musculoskeletal complications. These have an impact on mobility, participation and function for activities of daily living. Various postural management strategies are recommended to reduce symptoms and maintain body structure, including standing frames. A standing frame has a piece of equipment with a rigid frame and a wide base that supports a person in the standing position. There are a variety of proposed structural and functional benefits for standing frame use, including improved bone mineral density, hip stability and ranges of joint movement at the hip, knee and ankle, and those related to enhancing activity and participation. However, the evidence base for their use is limited. Standing frames may also be disadvantageous. Young people report pain and discomfort; families report increased demands on their time, which reduces family and young person participation. Furthermore, standing frames are expensive, require adaptation with the young person's growth, and use therapists' time to prescribe and monitor their use.

The National Institute for Health and Care Excellence (NICE) guideline for spasticity [NICE. *Spasticity in Under 19s: Management*. NICE Guideline (CG 145). NICE. 2012. URL: [www.nice.org.uk/guidance/cg145](http://www.nice.org.uk/guidance/cg145) (accessed 1 November 2017)] highlighted the limited evidence base for postural management programmes for young people with CP. However, little is known about current UK practice with respect to prescribing or actual use of standing frames. An understanding of this, along with stakeholders' perceptions of the acceptability and feasibility of a standing frames trial, is required.

## Aims and objectives

1. Aim 1: to determine current standing frame use in UK practice for the postural management of young people aged 1–18 years with CP and severe movement impairment [Gross Motor Function Classification System (GMFCS) levels IV and V].
  - i. Objective 1: conduct a survey (survey 1) of parents, health-care providers and education staff to determine current standing frame use for young people with CP.
2. Aim 2: to assess the willingness of parents to have their child randomised in a potential trial, including the acceptability of different treatment regimens, and to assess the preparedness of health-care providers to recruit to a potential randomised controlled trial.
  - ii. Objective 2: undertake qualitative research to explore attitudes to standing frame use and the acceptability of evaluating whether or not there is benefit through a trial or trials. This comprised (1) focus groups with parents, health-care providers and education staff and (2) in-depth interviews with young people.
  - iii. Objective 3: propose a small number of potential trial designs, structured around a population, intervention, comparison, outcome, timing, setting (PICOTS) framework and informed by the results of survey 1 and the qualitative research.
  - iv. Objective 4: conduct a second survey (survey 2) of parents, health-care providers and education staff regarding the acceptability and feasibility of these potential trial designs.
3. Aim 3: to propose a substantive trial design (or designs) that is informed by, and acceptable to, parents and health-care providers.

## Methods

We used a sequential mixed-methods design.

### Survey 1

The first stage of the study was a survey of current standing frame use for young people with CP with GMFCS levels IV or V (survey 1). The questions encompassed treatment indications, treatment goals, types of frame, duration of intended and actual use, and perceptions and practicalities of standing frame use. Three populations in the UK were sampled:

- professionals, such as physiotherapists, who prescribe standing frames for young people with CP (prescribing clinicians)
- professionals, such as paediatricians, orthopaedic surgeons, physiotherapists and education staff, who do not prescribe standing frames but work with young people with CP who use them (non-prescribing professionals)
- parents of young people (aged < 18 years) with CP who currently use or have used a standing frame (parents).

### Qualitative work

The next stage was qualitative to explore attitudes to standing frame use and acceptability of evaluating their benefit through a trial or trials. Five single stakeholder focus groups were conducted, one each for physiotherapists, medical professionals and education professionals, and two for parents. Young people with CP took part in in-depth interviews about using standing frames. After evaluating the results of these, two multistakeholder focus groups were convened to discuss the findings.

### Survey 2

A potential trial design, structured around a PICOTS framework was developed, based on the results of survey 1 and the qualitative research. A second survey (survey 2) regarding acceptability and feasibility of research and the potential trial design was conducted. Three populations in the UK were sampled:

- health professionals, such as physiotherapists and paediatricians, who work or have worked with young people with CP who use standing frames
- education professionals, such as teachers, who work or have worked with young people with CP who use standing frames
- parents of young people with CP who currently use or have used a standing frame.

## Study selection (inclusion criteria)

Eligibility of participants:

- Professionals (e.g. of health, education) who work or have worked with young people with CP who use standing frames could take part in the surveys and/or focus groups.
- Parent/carers of young people with CP who currently use or have used a standing frame could take part in the surveys and/or focus groups.
- Young people with CP aged 8–18 years who use or have previously used a standing frame could take part in the interviews.

People could take part in all suitable stages, with the exception of single stakeholder focus group participants, who could not participate in the multistakeholder focus groups.



## Data synthesis

The results from survey 1 (current UK standing frame practice), focus groups, interviews and survey 2 (acceptability and feasibility of a trial) were synthesised to provide recommendations for research.

## Results

### Survey 1

Survey 1 participants included:

- prescribing clinicians ( $n = 305$ )
- non-prescribing professionals ( $n = 155$ )
- parents ( $n = 91$ ).

The survey provided insight into current standing frame use. Prescribing practice was consistent across the UK, but achieving the prescribed use was not always possible due to resource, environmental, child and family factors. Professionals and parents of young people with CP were invested in using standing frames. They reported a variety of benefits; however, they also recognised many challenges associated with standing frame use.

### Qualitative work

There were three to nine participants in each single stakeholder focus group ( $n = 33$  participants). The single stakeholder focus groups added greater understanding to survey 1 results. Orthopaedic surgeons and physiotherapists had a strong belief that without standing frames there may be progressive deterioration in body structure and body function for young people with CP. The views of parents were entrenched in the idea that standing frames are good, and many were surprised to hear about the lack of robust evidence. A number of the proposed outcomes, particularly regarding body structure and body function, would require a longitudinal study in order to answer the question about the impact of standing frames. Other outcomes would be feasible to measure. There was no consensus regarding duration of intervention or comparators.

The interview participants were 12 young people with CP who were currently using or had used standing frames. The young people had clear opinions about standing frame use, but reported that they did not often get the chance to express them. Feelings about standing frames were unique to the individual; however, participation and activity engagement were particularly important to young people.

Two multistakeholder focus groups were convened, both in England: one in the North and one in the South. In the Northern group, participants were two education professionals (mainstream – classroom support assistants), one parent, one orthopaedic surgeon, one neurodisability paediatrician, one paediatric neurologist, one research occupational therapist and one physiotherapist. In the Southern group, participants were five physiotherapists, one community occupational therapist, one paediatrician, and one education professional (early years key worker). The multistakeholder focus groups added more in-depth clinical insight into potential trial designs for the different stakeholder groups. There were education barriers to overcome for all stakeholders as each person brought their unique experiences and biases when sharing their perceptions of the value of standing frames. Professionals, parents and young people were not in emotional equipoise despite understanding the evidential equipoise.

### Survey 2

Survey 2 explored the acceptability and feasibility of research trials. Participants included:

- health professionals,  $n = 467$
- education professionals,  $n = 44$
- parents,  $n = 74$ .

Most respondents believed that standing frames research is necessary and they were willing to engage in a trial. The maximum amount of time most health professionals and parents would agree to suspend standing frame use was 12 weeks. There were factors that would stop professionals and parents participating in a standing frames study, such as fear that suspending use would cause irreversible damage. Factors such as these are important when considering trial recruitment.

The collated study results (survey 1, single stakeholder focus groups, interviews, multistakeholder focus groups, survey 2) were presented in two multistakeholder design workshops. These design workshops discussed the (1) study's findings, (2) priorities for research studies, (3) potential trial designs and (4) conclusions and recommendations. Attendees at the design workshops included co-applicants, steering group members and various stakeholders such as physiotherapists, orthopaedic surgeons, paediatricians, parents and a young person with CP.

## Conclusions

Our findings suggest that a trial could examine standing frame use in young people with CP GMFCS III–V. The primary outcome of the trial should be selected from patient-reported outcomes (e.g. participation), with quality of life, subjective well-being, body function and body structure as secondary outcomes. There would be multiple factors to consider in a trial design including the heterogeneity of the population, significant challenges to recruitment and retention, and adherence to protocol. These challenges could be overcome by clinical understanding of the population and careful trial design, including an internal pilot.

A mixed-methods approach that captures quantitative and qualitative data about users' experience would be necessary. We have shown that it is possible to obtain young people's views, which are highly valuable with respect to their engagement in clinical intervention and research.

Despite the publication of the *International Classification of Functioning, Disability and Health* in 2001 [World Health Organization (WHO). *International Classification of Functioning, Disability, and Health: ICF*. Geneva, Switzerland: WHO; 2001] [and the *Children and Youth Version* in 2007 (WHO. *International Classification of Functioning, Disability, and Health: Children & Youth Version: ICF-CY*. Geneva, Switzerland: WHO; 2007)], research and clinical focus still tends to be directed only at body structure and body function. To engage stakeholders in a trial, there would need to be explanation of why measures of patient-reported outcomes (e.g. quality of life, participation and subjective well-being) were important clinical outcomes.

## Recommendations for research

We present here our recommendations for a research trial, using the PICOTS framework.

### **Population: young people with cerebral palsy (Gross Motor Function Classification System III–V)**

A study in those of infant and primary school age (4–11 years) is likely to be the most practical, with respect to ease of facilitation of standing frame use in school, size of standing frames and the typical age range in which most young people with CP start using standing frames.

The commissioned call suggested research into young people with CP GMFCS IV and V; however, our survey showed that standing frame use in younger people with GMFCS III was widespread, in keeping with our clinical experience, and we therefore recommend that inclusion criteria should include young people with CP GMFCS III.

***Intervention: standing frame use (3 days per week)***

We found that the recommended standing frame use was for 30–60 minutes a day for  $\geq 5$  days each week but that this was not usually achieved. Pragmatically, standing frame intervention for a duration tolerated by the young person for 3 days per week would be an appropriate dosage based on the results from survey 1 (UK standing frame practice).

***Comparator: no standing frame use***

Standing frame use versus no use, or versus alternative therapy or equipment (e.g. hydrotherapy or disability exercise bike) was discussed in detail throughout the study. Consensus suggests that standing frame use versus no use would be feasible and most likely to detect change. All young people would be likely to have other therapy, orthotics and activities regardless of whether they were in the intervention or non-intervention group ('treatment as usual') but randomisation should lead to a balance with respect to these factors across trial groups.

***Outcomes: selected from patient-reported outcomes (e.g. participation), body function and structure***

- Primary outcome:
  - a selected patient-reported outcome (participation).
- Secondary outcomes:
  - patient-reported outcomes not included as a primary outcome (e.g. quality of life, subjective well-being)
  - body function (including bowel function, speech, breath control and feeding)
  - body structure (including loss of range of movement).

Measurement tools should address the primary and secondary outcomes of study. Patient-reported outcome measures could assess quality of life, participation and subjective well-being. All measures should ideally be adaptable to the young person's communication level and cognitive ability. There may be a need for parent- or education staff-proxy reports of the child's patient-reported outcomes (quality of life, participation and subjective well-being), although the ideal would be a young person's self-report. It will also be important to assess impact on parents and family life. Secondary outcome measures of body function may include respiratory function, bowel function and pain; and of body structure may include clinical measures of joint range of movement and growth.

***Timing: 6–12 weeks***

Through survey 1 and the qualitative work, we found that young people often had a break from using standing frames during school holidays. Survey 2 demonstrated that suspending or delaying standing frame use would be acceptable and ethical for a period of 6–12 weeks. However, qualitative data from parents reflecting on past experiences revealed that delayed use (i.e. a waiting list control design) would not be an acceptable trial design. Therefore, we recommend suspended use for 6–12 weeks.

***Setting: specialist school environment***

Standing frame use in the specialist school environment is recommended because this is where most young people with CP GMFCS III–V are educated. Specialist schools would be better equipped to support standing frame use for the purposes of a trial as they tend to be used in this environment anyway. However, there may be challenges with education, training and support of education professionals in conducting a trial in that setting. For adequate statistical power, a trial would need multicentre recruitment.

## Implications for health care

It is important to note that lack of evidence to support standing frame use in young people with CP does not necessarily imply lack of benefit. Many stakeholders (including young people with CP) perceive positive outcomes associated with standing frame use despite the paucity of evidence. As such, standing frames may continue to be prescribed and used even if a future trial demonstrates that they are not effective. Participants suggested that there would need to be evidence of standing frames causing harm in order for people to stop using them.

## Funding

Funding for this study was provided by the Health Technology Assessment programme of the National Institute for Health Research.

# Chapter 1 Background and aims

## Context

Cerebral palsy (CP) affects 1 in 400 children and young people. CP is associated with spasticity and secondary musculoskeletal complications. Twenty-five per cent of young people with CP are non-ambulant [Gross Motor Function Classification System (GMFCS) levels IV or V].<sup>1,2</sup> These young people frequently experience joint contractures, loss of bone mineral density (BMD), fractures and hip dislocation, leading to pain and progressive disability.<sup>3</sup> Postural management, including standing frame use, is recommended<sup>4</sup> and widely used in clinical practice for young people with CP. A standing frame has a rigid frame with a wide base. A child is positioned in the standing frame with variable support that may enable movement of the head, upper body and upper limbs, thus potentially improving their function and participation. For the lower limbs, standing is usually passive (i.e. continuous and stationary loading) but can be dynamic (i.e. simulating the forces applied during natural walking). Standing frames are predominantly used in non-ambulant young people (GMFCS III–V), but in the younger age range it may also be used in those with some independent mobility (GMFCS III).

## Research objectives

The overall purpose was to answer the question: what is the likely acceptability of a trial to determine the clinical effectiveness of standing frames? To do this, we undertook two surveys as well as focus groups and in-depth interviews to assess the feasibility and potential design of a trial (or trials) of standing frame use for young people with CP.

## Aims and objectives

Aim 1. To determine current standing frame use in UK practice for the postural management of young people with CP aged 1–18 years with severe movement impairment (GMFCS IV and V).

This aim was addressed by:

- Objective 1: conduct a survey (survey 1) of parents, health-care providers and education staff to determine current standing frame use for young people with CP. The questions comprised treatment indications, treatment goals, types of frame, duration of intended and actual use, and perceptions and practicalities of standing frame use.

Aim 2. To assess the willingness of parents to have their child randomised in a potential trial, including the acceptability of different treatment regimens, and to assess the preparedness of health-care providers to recruit to a potential randomised controlled trial (RCT).

This aim was addressed by:

- Objective 2: undertake qualitative research to explore attitudes to standing frame use and acceptability of evaluating their benefit through a trial or trials. This comprised (1) focus groups with parents, health-care providers and education staff and (2) in-depth interviews with young people.
- Objective 3: propose a small number of potential trial designs, structured around a population, intervention, comparison, outcome, timing, setting (PICOTS) framework and informed by the results of survey 1 and the qualitative research.

- Objective 4: conduct a second survey (survey 2) of parents, health-care providers and education staff regarding the acceptability and feasibility of these potential trial designs.

Aim 3. To propose a substantive trial design (or designs) that is informed by, and acceptable to, parents and health-care providers.

This aim was addressed by:

- Objective 5: combine the results from survey 1, focus groups, interviews and survey 2 to develop a substantive trial design or designs.

## Literature review

A consensus statement<sup>4</sup> recommended the use of standing frames as part of a postural management programme for young people with CP (GMFCS IV and V) from the age of 12 months, but acknowledged the lack of an evidence base for this intervention; the evidence that there was came from small case series, which were not blinded or randomised.

Reviews of standing frames<sup>5–7</sup> and this Health Technology Assessment (HTA) programme-commissioned call concurred that the evidence base was limited. The most recent review<sup>7</sup> claimed a positive effect on BMD, hip stability and joint range of movement at the hip, knee and ankle with variable duration of standing frame use, but Fehlings *et al.*<sup>6</sup> found the evidence unconvincing. Frames may also be disadvantageous. Young people have reported pain and discomfort, and families have reported increased demands on their time.<sup>5</sup> Furthermore, standing frames are expensive (they cost around £800–2500 each), require adaptation with the young person's growth and use therapist time to prescribe and monitor their use. We are aware of a UK group currently conducting a systematic review of supported standing in CP, although we were advised that it will not be published until 2018 (Rachel Rapson, Bidwell Brook School, 2017, personal communication).

Gibson *et al.*<sup>8</sup> conducted a small case series that examined the effect of standing frame use for 1 hour every day for 6 weeks in five non-ambulant young people with CP, aged 6–9 years. Two 6-week intervals of standing frame use were alternated with two 6-week periods of no standing frame use. There was a suggestion of an improvement regarding hamstring stretches with standing frame use.

Caulton *et al.*<sup>9</sup> reported a RCT of a standing frame programme on BMD in 26 prepubertal young people (aged 4–11 years) with CP. This was a heterogeneous group, paired according to vertebral and tibial BMD scores and then randomised to either their usual standing duration or 50% increased duration of standing. There was, on average, an increase of 6% in vertebral BMD in the intervention group but no significant change in proximal tibial BMD in either group. The authors concluded that by increasing vertebral BMD through increased duration of standing there might be a potential to reduce risk of vertebral fractures. However, National Institute for Health and Care Excellence (NICE) guidance<sup>10</sup> recommends that standing frames should not be used for the sole purpose of preventing low BMD.

There is variability in the amount of weight bearing in different standing frames, which may affect BMD outcomes.<sup>11</sup> Dynamic standing interventions may have more potential to improve bone health than passive standing frames.<sup>12</sup>

## How did the literature inform this study?

Synthesis of the literature revealed evidential equipoise (i.e. conflicting results from a weak evidence base). This justifies the need for further study, particularly to better understand the impact of standing frames at different stages in the lives of individuals with CP, with respect to their participation and subjective well-being rather than simply changes in their body structure and body function.

## Current practice in the use of standing frames

Little is known about current UK practice with respect to the prescribing or actual use of standing frames, at home or in the community. Clinical experience from co-applicants suggests that most young people with CP have a physiotherapy programme that includes standing frame use, but prescription, timing, and dosage of intervention may be varied. To our knowledge, there is no previously published description of current UK practice.

## Why this research is needed

There is a large population for whom obtaining clarity on the benefits of standing frame use is important. The birth prevalence of CP is about 2.5 per 1000 live births, so approximately 1740 CP births annually in England and Wales.<sup>13</sup> Approximately 25% of young people with CP are GMFCS level IV or V, and are therefore likely to have standing frames considered as part of their postural management.

The potential impact of standing frame use extends beyond childhood. Life expectancy in those with GMFCS level IV or V cannot be precisely estimated because published studies use different classifications of severity; however, 89% of those with only motor impairment and who need a self-propelled wheelchair lived to age 30 years, and 42% of those who could not self-propel lived to age 30 years.<sup>14</sup>

For a young person, a standing frame may reduce risks of joint contractures, hip dysplasia and scoliosis. It may improve BMD and increase the likelihood, as a non-ambulant adult, that they will be able to assist a caregiver in a standing or weight-bearing transfer. It may reduce pain and make daily care easier. By enabling the young person to be vertical, a standing frame may improve head and trunk control; fine motor skills; gastrointestinal, bladder and respiratory function; self-esteem; and social, communicative and exploratory participation.<sup>7</sup>

However, these are only potential benefits. The NHS needs to know if these benefits are real, given that there are significant cost implications of use and also reported negative effects: some young people experience discomfort in standing frames, and families and education staff describe practical difficulties in their use.<sup>15</sup>

If there is clinical benefit in the use of standing frames, then the costs need to be balanced against the cost of long-term health-care needs (including quality of life), and secondary musculoskeletal complications of spasticity in CP, such as management of hip migration and dislocation, neuromuscular scoliosis, pathological fractures, pain and respiratory compromise that might have been prevented.

The NICE guideline<sup>16</sup> for spasticity highlighted the limited evidence base for all interventions for young people with spasticity and specifically for postural management programmes. NICE proposed a trial of standing frame use for young people aged 1–3 years with GMFCS level IV or V. Our study was designed in the light of the 2013 National Institute for Health Research (NIHR) HTA commissioning brief, which widened the question to include young people < 18 years. We agreed that this was appropriate because of clinical indications for frames and changing neurodevelopmental profiles of young people at different ages.

A future trial of standing frame use would also fit with the CMO's 2012 annual report<sup>17</sup> which highlighted the need for research into effective intervention for long-term conditions in childhood, particularly in neurodevelopmental disorders where the health needs may be great but for which the evidence base for interventions is weak. A standing frames trial also aligns with the top research question identified for young people with neurodisability:<sup>18</sup> does the timing and intensity of therapies alter the clinical effectiveness of therapies for infants and young children with a neurodisability? This includes strategies, dosage and direction of therapeutic interventions.

Co-applicant clinical experience shows that some parents and professionals have strong preformed views about standing frame use. Some professionals may have opinions that have been informed by their training or subsequent clinical experience, and this may lead them to making persuasive arguments to parents despite the weak evidence base. Parents in turn may have invested time, effort and faith in standing frames. Thus, although the current paucity of evidence demonstrates a clear need for evaluative research, a substantive trial will be difficult to design. The challenges for trial design arise from the heterogeneity of current practice regarding the purpose and delivery of standing frame intervention, and the many variables in each of the PICOTS frameworks that need to be considered. Depending on the young person's neurodevelopmental profile and the goal of standing frame use, a variety of different comparators in a trial may be appropriate.

Furthermore, parents, professionals and young people report benefits of standing frames with respect to activity and participation that is not included in the current literature and has not been explored. Research needs to consider further aspects of the International Classification of Functioning, Disability and Health: Children and Youth version (ICF-CY),<sup>19</sup> such as participation factors, along with body structure. The ICF-CY is a useful framework for examining the impact of the surrounding environment (including therapeutic interventions such as standing frames) and individual characteristics on a young person's health-related functioning; it encompasses functions and structures of the body, activity, participation, personal factors and environmental factors.

This study was designed to address these issues and consider how a trial could be designed by determining current UK practice in the use of standing frames for young people with CP and by consultation with young people, parents and professionals who use standing frames.



## Chapter 2 Methodology

During the conduct of this study we adopted a view of health as conceptualised by the ICF-CY.<sup>19</sup>

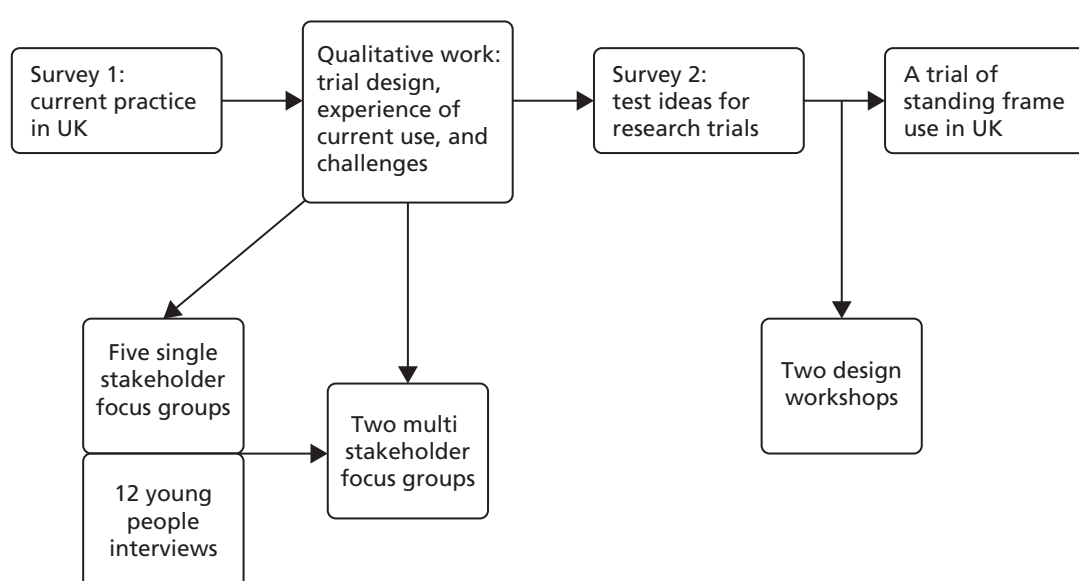
We used a sequential mixed-methods design, as outlined in *Figure 1*, whereby the findings from each stage informed the subsequent stage. The quantitative and qualitative findings are synthesised in *Chapters 9* and *10*. This process involved accounting for convergence (i.e. providing research recommendations) and divergence (i.e. highlighting potential challenges) between the data sources. People could take part in all stages if eligible, with the exception of the multistakeholder focus groups. Single stakeholder focus group participants could not participate in the multistakeholder focus groups.

There were multiple study populations: prescribing professionals, professionals who work with standing frame users, parents of young people who currently use or have previously used a standing frame and young people who currently use or have previously used a standing frame.

### Analysis

Quantitative data analysis was descriptive, largely reporting percentages of respondents in each category for each question. For survey 2, if there was a large spread of responses for particular items, the related open-ended responses were examined and then grouped into themes to explore the reasons behind participants' closed-answer choices.

The qualitative analysis was informed by the framework method,<sup>20</sup> which is not aligned with a particular epistemological or philosophical approach.<sup>21</sup> The framework method was chosen because it allowed for systematic data analysis that was accessible for our multidisciplinary research team. *Table 1* outlines the stages of analysis. We used a deductive–inductive approach; although certain themes and codes were preselected based on the ICF-CY or the PICOTS, any new themes that were elicited were added to the framework and codes were then created. NVivo qualitative data analysis software version 11 (QSR International, Warrington, UK) was used to manage the data.



**FIGURE 1** Flow of sequential mixed-methods design.

**TABLE 1** Stages of framework method analysis

| Stage | Description  |
|-------|--|
| 1     | Verbatim transcription   |
| 2     | Familiarisation with the interview (e.g. reading and rereading transcripts, relistening to the audio-recording)  |
| 3     | Coding as per the ICF-CY. Although deductive coding was used, some open coding took place at this stage to ensure that important aspects of the data were not missed |
| 4     | Developing a working analytical framework through discussion and definition of labels after coding the first three interviews  |
| 5     | Applying the analytical framework by indexing subsequent transcripts using existing codes  |
| 6     | Charting data into the framework matrix (i.e. data were summarised by category for each transcript, with illustrative quotations)                                    |
| 7     | Interpreting the data through discussion, reflection and writing up  |

## Reflexivity

All of the research team were active in disability research. Anna Basu, Jill Cadwgan, Sarah Crombie, Andrew Roberts, Jeremy R Parr, Keith Miller and Niina Kolehmainen work clinically with young people with CP who use standing frames. Johanna Smith is a parent of a young person with CP who uses a standing frame.

## Mixed-methods design

A mixed-methods (qualitative and quantitative) design was chosen to provide a comprehensive means of researching this topic. Mixed-methods research has many benefits such as the ability to have an exploratory approach (rather than needing clear hypotheses), richer data from a variety of stakeholders and greater confidence in research findings through a holistic examination. Using only quantitative methods can produce results that may not reflect stakeholders' experiences accurately because the researchers' own agendas are driving the study. Using only qualitative methods can produce findings that are not generalisable to the understanding or prediction of issues affecting the wider population. Using both allows for weight to be given to the meanings, experiences and views of a variety of stakeholders.<sup>22</sup> Another advantage is that paradoxes between the data sources can open up new ways of thinking about a particular topic and enable further theory conceptualisation and the creation of recommendations for future research.<sup>23</sup>

## Trustworthiness in qualitative research

Each focus group was facilitated by Jane Goodwin and Jan Lecouturier, with the exception of the physiotherapist focus group (JG and SC) and the medical professional focus group (JG and JC). Sarah Crombie (Physiotherapist) and Jill Cadwgan (Consultant Paediatrician In Neurodisability) were chosen as secondary facilitators in the focus groups related to their discipline because it was anticipated that their specialist knowledge would be necessary to facilitate an in-depth discussion, including answering any clinical questions. Jane Goodwin conducted all of the interviews.

We approached clinicians who completed survey 1, personal contacts and professional networks (including via social media); however, it was difficult gathering a group of clinicians at the same time in the same place for a research focus group owing to their clinical commitments and other responsibilities. Two members of the research team (KM and AR) participated in the clinician single stakeholder focus group as we experienced

trouble with recruitment (including having two clinicians recruited to the focus group who did not show up on the day due to urgent clinical commitments), and because they met eligibility criteria for the target population.

All qualitative data were analysed by Jan Lecouturier and Jane Goodwin. Although they had experience in disability research, they were naive about standing frames in research and clinical practice. This meant that they were fully in equipoise at the point of data collection. They had a greater awareness of stakeholders' views about standing frames at the end of the focus groups and interviews, but, as these views were mixed, it is unlikely that they would have had any influence on the interpretation of the data at the analysis stage. They also independently coded all transcripts. A robust discussion followed to resolve any discrepancies, of which there were few. The coding was discussed and clarified with the co-applicants as a means of quality control and rigour check. Clinical members of the co-applicant team (e.g. JC, SC and AB) and the parent co-applicant (JS) were available to sense check the meaning of the transcripts and advise on the interpretation. Each researcher remained conscious of their biases to avoid them negatively influencing the analysis and write up. However, it is important to note that the researchers' relevant knowledge and experience was also a strength because it allowed for in-depth engagement with the data, including unexpected themes. The transcripts and recordings were referred to continuously to ensure that the analysis and interpretation were staying true to the data. Quotations from participants are provided as supporting evidence for the themes. The transparent audit trail in NVivo 11 accounted for the systematic examination at each level of analysis.

## Patient and public involvement

Patient and public involvement (PPI) was vital to this study from the outset; we outline PPI contributions at each stage. PPI was important for piloting surveys, creating topic guides and providing advice on interviewing young people with CP. A nominated Research Advisory Group (RAG) with six parents of young people with CP was convened. The parents were approached through the parent co-applicant's (JS's) contacts. A flexible approach to PPI was taken; as a result of the nature of parents' caring roles and the complexity of CP, it was difficult at times for our nominated RAG to engage as outlined in the study timelines. Therefore, informal discussions with families known to the co-applicant team were held throughout, as well as two design workshops after all the data had been collected. In addition, the North East Young Persons Advisory Group was approached, with co-applicant Johanna Smith presenting and receiving feedback on study content at two of its meetings. This group comprises teenagers in the local area who are interested in medical research. Although at the time of our contact there were no members with CP, some had siblings or friends affected by disability. The young people provided invaluable input on how to engage young people in research and PPI. They also contributed extensively to a booklet of interview findings, which was then sent to the young people who participated in the interviews.

We learnt valuable lessons about the involvement of parents in PPI. We found that an online RAG allowed parents to engage in the study on their own terms [six parents joined a private Facebook (Facebook, Inc., Menlo Park, CA, USA; [www.facebook.com](http://www.facebook.com)) group for this purpose]. For example, they could provide feedback on documents in their own home after their children had gone to bed. Furthermore, the parent co-applicant (JS) ensured that the study was grounded in what was accessible (e.g. language used in documents), acceptable and reasonable (e.g. appropriate times to approach for consent), and feasible (e.g. which trial designs would be possible pragmatically) for families at all times. For example, from a research design perspective, a trial could (in theory) have recruited families to a 'delayed start' research study at the time of standing frame prescription because many families have a lengthy waiting period before receiving the prescribed standing frame anyway. Although acceptable to other participant groups, parent participants had commented that this would be unacceptable because it would be around the same time as the child's CP diagnosis. Given the amount of complex information being processed by families during this time it would be difficult to ascertain informed consent to participate in a research trial. The appropriate weight may not have been given to the parents' voices if Johanna Smith had not continued to speak on their behalf in research team meetings.

## Research Ethics Committee approval and study governance

The study sponsor was Newcastle upon Tyne Hospitals NHS Foundation Trust. The research was approved by the Health Research Authority East Midlands – Nottingham 1 Research Ethics Committee (15/EM/0495, 9 December 2015).

## Changes to the protocol

Originally, the protocol stated that four of the focus groups would be single stakeholder, one each for parents, therapists, medical staff (orthopaedic surgeons and paediatricians) and educational professionals. However, the parent co-applicant (JS), PPI advisors and other parents highlighted that it would be difficult for parents to travel long distances to attend a focus group, and that there may be important differences in opinion that are associated with where the parents live. After discussion, we decided to convene two parent focus groups, one in the north of England and one in the south. This was a substantial amendment and, therefore, required review and approval from the Research Ethics Committee. These were the only changes to the protocol (version 4, May 2016).

Initially, participants in the multistakeholder focus groups were going to be selected from those who had previously taken part in the single stakeholder focus groups. After co-applicant discussion, we decided to recruit new participants for the multistakeholder groups. This was because our knowledge about the acceptability and feasibility of a research trial had evolved, and we did not want to replicate the discussion in the single stakeholder focus groups.

# Chapter 3 Survey 1: UK standing frame practice

## Objectives

A survey was conducted from March to May 2016 to determine current UK standing frame practice, as well as the perceived benefits and challenges of standing frame use.

## Methods

### Population

Three populations in the UK were sampled:

1. professionals, such as physiotherapists, who prescribe standing frames for young people with CP
2. professionals, such as paediatricians, orthopaedic surgeons, physiotherapists, and education staff, who do not prescribe standing frames but work with young people with CP who use them
3. parents of young people (aged < 18 years) with CP who currently use or have used a standing frame.

### Questionnaire development: UK standing frame practice

A questionnaire was developed to explore current standing frame practice. Following a literature review, parents and paediatric health professionals were consulted regarding ideas for appropriate questionnaire content. Based on this information, the co-applicant study group devised the content of the questionnaires, drawing on their clinical expertise and background experience of survey design for similar studies. Multiple drafts were circulated via e-mail and discussed prior to production of the three final drafts, that is, separate versions for the three populations sampled for this study (prescribers, professionals and parents). These drafts were then piloted with a small number of people known to the researchers (i.e. three prescribers, six professionals and five parents. Prescribers and professionals who worked across both private practice and the public sector were asked to respond in relation to their public sector work). Based on PPI advice, piloting using cognitive interviews was considered but rejected. The individuals provided feedback regarding the comprehensibility and acceptability of the questions and associated instructions, as well as the usability and technical functionality of the electronic questionnaire. Minor changes, such as wording and question logic, were made at this time. The authors then reviewed the questionnaires again in a co-applicant meeting prior to dissemination.

The final survey questions comprised: (1) demographic characteristics of respondents, (2) experience and use of standing frames as part of a postural management programme for young people with CP, (3) factors influencing standing frame choice and prescribing practice, (4) challenges of standing frame use, (5) indications for prescribing standing frames and (6) perceived benefits of standing frame use. The survey also identified any differences between recommended or prescribed use versus actual use. Most questions offered fixed-choice responses, though there were some brief free-text responses. Participants could use a 'back' button to review or change their answers as required (see *Appendices 1–3*).

### Procedure

A convenience sample of prescribing clinicians and non-prescribing professionals were approached through relevant national royal colleges, professional bodies and their national newsletters, and child development teams via the British Academy of Childhood Disability. Parents were approached via clinical services located in the North, South, and West Midlands of England, and through the following national organisations: the National Network of Parent Carer Forums, Contact a Family and the Peninsula Cerebra Research Unit for Childhood Disability Research. In addition, we approached parents directly through school newsletters and peer-to-peer support groups. Facebook pages (e.g. Cerebra) and the study's Twitter (Twitter, Inc., San Francisco,

CA, USA; [@UnderstandFrame](https://www.twitter.com/UnderstandFrame)) were used to allow those interested to link to the study website (<https://research.ncl.ac.uk/understandingframes/>) and access the questionnaire. A £10 voucher was offered to all who completed the questionnaire.

Recruitment was UK-wide and took place between March and May 2016. The survey questionnaires were hosted on SurveyMonkey® (Palo Alto, CA, USA), with paper versions available on request. E-mail and web-based flyers were sent to potential participants with a link to the appropriate version of the questionnaire.

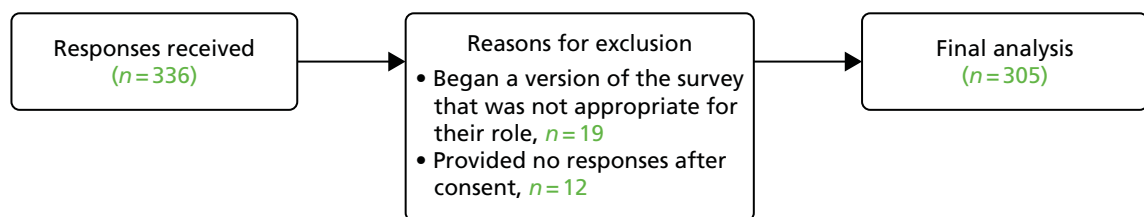
## Results

### Participants

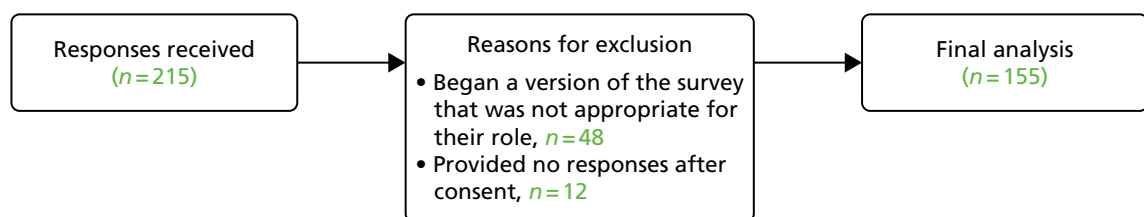
Numbers included in the final analysis are presented here. *Figure 2* indicates participant flow through the study from responses received to responses included in the final analysis.

- Prescribing clinicians: professionals, such as physiotherapists, who prescribe standing frames for young people with CP,  $n = 305$ .
- Non-prescribing professionals: professionals, such as paediatricians, orthopaedic surgeons, physiotherapists and education staff, who do not prescribe standing frames but work with young people with CP who use them,  $n = 155$ .
- Parents: parents of young people with CP who currently use or have used a standing frame,  $n = 91$ .

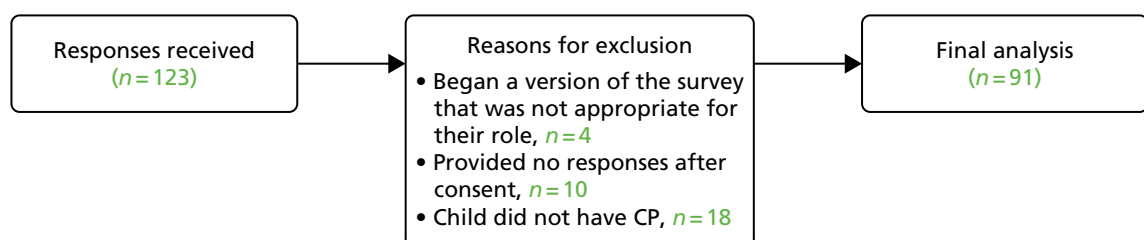
#### Prescribing clinicians



#### Non-prescribing professionals



#### Parents



**FIGURE 2** Survey 1: participant flow through the study from responses received to responses included in the final analysis.

Tables 2 and 3 outline the respondent characteristics. Most prescribing clinicians and a large number of non-prescribing professionals were physiotherapists working in community settings. The majority had > 10 years' experience and used a variety of standing frame types.

**TABLE 2** Characteristics of the two professional groups

| Characteristics  | Prescribing clinicians,<br><i>n</i> (%) | Non-prescribing professionals,<br><i>n</i> (%) |
|--|---|--|
| Occupation   |   |  |
| Physiotherapist  | 302 (99)                                | 49 (31.6)                                      |
| Occupational therapist   | 1 (0.3)                                 | 39 (25.2)                                      |
| Paediatrician  | 0                                       | 29 (18.7)                                      |
| Classroom teacher or support teacher                                       | 0                                       | 15 (9.6)                                       |
| Therapy assistant or technical instructor                                  | 1 (0.3)                                 | 11 (7.1)                                       |
| Other health professional  | 0                                       | 7 (4.5)  |
| Technician – engineering background  | 0                                       | 3 (1.9)  |
| Orthopaedic surgeon  | 0                                       | 2 (1.3)  |
| Missing  | 1 (0.3)                                 | 0  |
| Current working environment <sup>a</sup>                                   |   |  |
| Inpatients   | 34 (11.1)                               | 32 (20.6)                                      |
| Outpatients  | 153 (50.2)                              | 77 (49.7)                                      |
| Community – home   | 263 (86.2)                              | 79 (51)  |
| Community – education centre (school/preschool)                            | 279 (91.5)                              | 107 (69)                                       |
| Other  | 1 (0.3)                                 | 6 (3.9)  |
| Missing  | 4 (1.3)                                 | 2 (1.3)  |
| Number of children on current case load who are prescribed standing frames |   |  |
| < 10 children  | 126 (41.3)                              | 66 (42.6)                                      |
| 11–20 children   | 123 (40.3)                              | 35 (22.6)                                      |
| 21–30 children   | 23 (7.5)                                | 12 (7.7)                                       |
| > 30 children  | 21 (6.9)                                | 20 (12.9)                                      |
| Missing  | 12 (3.9)                                | 8 (5.2)  |
| Did not know   | –                                       | 14 (9)   |
| Years working with children who use standing frames                        |   |  |
| < 2  | 25 (8.2)                                | 14 (9)   |
| 2–5  | 44 (14.4)                               | 24 (15.5)                                      |
| 6–10   | 59 (19.3)                               | 32 (20.6)                                      |
| > 10   | 173 (56.7)                              | 83 (53.5)                                      |
| Missing  | 4 (1.3)                                 | 2 (1.3)  |

continued

**TABLE 2** Characteristics of the two professional groups (*continued*)

| Characteristics   | Prescribing clinicians,<br><i>n</i> (%) | Non-prescribing professionals,<br><i>n</i> (%) |
|---|---|--|
| Groups of children with whom the clinicians work <sup>a</sup> |   |  |
| GMFCS I   | 15 (4.9)                                | 9 (5.8)  |
| GMFCS II  | 79 (25.9)                               | 33 (21.3)                                      |
| GMFCS III   | 244 (80)                                | 74 (47.7)                                      |
| GMFCS IV  | 289 (94.8)                              | 105 (67.7)                                     |
| GMFCS V   | 277 (90.8)                              | 95 (61.3)                                      |
| Would rely on prescriber                                      | –                                       | 25 (16.1)                                      |
| Reported not familiar with GMFCS                              | 5 (1.6)                                 | 12 (7.7)                                       |
| Missing   | 12 (3.9)                                | 9 (5.8)  |
| Experience with types of standing frame <sup>a</sup>          |   |  |
| Fixed prone standing frame                                    | 282 (92.5)                              | 116 (74.8)                                     |
| Upright standing frame  | 282 (92.5)                              | 136 (87.7)                                     |
| Supine standing frame   | 281 (92.1)                              | 111 (71.6)                                     |
| Dynamic frame   | 162 (53.1)                              | 53 (34.2)                                      |
| Sit-to-stand frame  | 116 (34.8)                              | 33 (21.3)                                      |
| Missing   | 13 (4.3)                                | 12 (7.7)                                       |

<sup>a</sup> Percentages > 100% because participants could choose more than one option.

**TABLE 3** Characteristics of the young people whose parents responded

| Children whose parents responded                                     | <i>n</i> (%) |
|--|--------------|
| Child's distribution of CP   |              |
| Whole body   | 72 (79.1)    |
| Both sides of the body but legs more than arms                       | 14 (15.4)    |
| One side of the body only  | 5 (5.5)      |
| Missing  | 0            |
| Child's school type <sup>a</sup>                                     |              |
| Specialist school  | 68 (74.7)    |
| Mainstream   | 29 (31.9)    |
| College (post 16 years of age, with additional or special provision) | 5 (5.5)      |
| Other  | 11 (12.1)    |
| Missing  | 4 (4.4)      |
| Child's age (years)  |              |
| > 10   | 46 (50.5)    |
| 6–10   | 25 (27.5)    |
| 2–5  | 14 (15.4)    |
| < 2  | 1 (1.1)      |
| Missing  | 5 (5.5)      |



**TABLE 3** Characteristics of the young people whose parents responded (*continued*)

| Children whose parents responded                                     | n (%)     |
|--|-----------|
| Child's estimated GMFCS level  |           |
| GMFCS I or II  | 8 (8.8)   |
| GMFCS III  | 20 (22)   |
| GMFCS III or IV  | 10 (11)   |
| GMFCS IV   | 36 (39.6) |
| GMFCS V  | 17 (18.7) |
| Missing  | 0         |
| Experience with types of standing frame <sup>a</sup>                 |           |
| Fixed prone standing frame   | 34 (37.4) |
| Upright standing frame   | 43 (47.3) |
| Supine standing frame  | 32 (35.2) |
| Dynamic frame  | 10 (11)   |
| Sit-to-stand frame   | 6 (6.6)   |
| Missing  | 0         |
| Funding source for standing frame <sup>a</sup>                       |           |
| Statutory services (health, social care or education)                | 76 (83.5) |
| Charity funding  | 7 (7.7)   |
| Private or self-funding  | 7 (7.7)   |
| Did not know   | 3 (3.3)   |
| Missing  | 8 (8.8)   |
| Professional who assessed and fitted the standing frame <sup>a</sup> |           |
| Physiotherapist  | 78 (85.7) |
| Occupational therapist   | 23 (25.3) |
| Frame manufacturer or representative                                 | 21 (23.1) |
| Paediatrician  | 2 (2.2)   |
| Therapy assistant or technical instructor                            | 5 (5.5)   |
| Did not know   | 3 (3.3)   |
| Missing  | 8 (8.8)   |
| Professional who monitors the use of the standing frame <sup>a</sup> |           |
| Physiotherapist  | 74 (81.3) |
| Occupational therapist   | 25 (27.5) |
| Frame manufacturer or representative                                 | 6 (6.6)   |
| Therapy assistant or technical instructor                            | 8 (8.8)   |
| Paediatrician  | 1 (1.1)   |
| Did not know   | 2 (2.2)   |
| Missing  | 14 (15.4) |

<sup>a</sup> Percentages add up to > 100% because participants could choose more than one option.

Sixty-five per cent of parents had children who used or had used only one type of standing frame that was assessed, fitted and monitored by a physiotherapist. The standing frames were generally funded by statutory services (see *Table 3*).

Children of the parent respondents were aged 1–18 years (median 10 years and 6 months). They began standing frame use at 1–11 years (median 3 years) and stopped use at 3–16 years (median 9 years and 7 months). Waiting times to receive a standing frame after it had been recommended ranged between the response options 'less than 4 weeks' and 'more than 26 weeks' (see *Table 8*).

Patient and public involvement work had indicated that asking parents to categorise their child based on their GMFCS level was inappropriate. Therefore, we estimated the GMFCS level from reported information about independent walking, use of mobility aids, weight bearing and maintenance of head position. However, for ten young people, it was not possible to determine whether they were GMFCS III or GMFCS IV based on the information provided. We therefore categorised them as 'GMFCS III or IV' (see *Table 3*).

### **Prescribing practice and actual use of standing frames**

Standing frame recommendations and prescriptions for use were primarily based on clinical experience rather than national or local guidance, as reported by both non-prescribing professionals and prescribing clinicians (81% and 89%, respectively).

Of prescribing clinicians, 82% suggested that standing frames should be used daily; however, only 21% of parents reported that this was achieved. Furthermore, 76% of prescribers recommended that the duration of standing should be 30–60 minutes, yet only 39% of parents reported this duration of use (*Tables 4–6*). In terms of frequency of standing frame use, 59% of parents reported at least as much use as prescribed, and 91% reported a duration at least as much as described (see *Tables 5 and 6*).

**TABLE 4** Professionals' prescribed standing frame use

| Frequency and duration of use   | Prescription of prescribing clinicians, <i>n</i> (%) | Views of non-prescribing professionals, <i>n</i> (%) |
|---------------------------------|--|--|
| Frequency of use                |  |  |
| Every day                       | 251 (82.3)   | 93 (60)  |
| More than three times each week | 38 (12.5)  | 15 (9.7)   |
| More than once each week        | 0  | 0  |
| Once each week                  | 0  | 0  |
| Less than once each week        | 0  | 0  |
| Did not know                    | –  | 27 (17.4)  |
| Missing                         | 16 (5.2)   | 20 (12.9)  |
| Duration of standing            |  |  |
| < 30 minutes                    | 9 (3)  | 4 (2.6)  |
| 30–60 minutes                   | 233 (76.4)   | 66 (42.6)  |
| 1–2 hours                       | 46 (15.1)  | 18 (11.6)  |
| > 2 hours                       | 1 (0.3)  | 1 (0.6)  |
| Did not know                    | –  | 46 (29.7)  |
| Missing                         | 16 (5.2)   | 20 (12.9)  |

'–' indicates that the item was not a response option for that group of participants.

**TABLE 5** Parent report of frequency of prescribed and actual standing frame use

| Prescribed use <sup>a</sup>     | Actual use <sup>a</sup> |                                 |                          |                |                          |              |
|---------------------------------|-------------------------|---------------------------------|--------------------------|----------------|--------------------------|--------------|
|                                 | Every day               | More than three times each week | More than once each week | Once each week | Less than once each week | Did not know |
| Every day                       | 13                      | 5                               | 6                        | 0              | 1                        | 0            |
| More than three times each week | 1                       | 7                               | 1                        | 1              | 0                        | 1            |
| More than once each week        | 0                       | 0                               | 1                        | 1              | 1                        | 0            |
| Once each week                  | 0                       | 0                               | 0                        | 1              | 0                        | 0            |
| Less than once each week        | –                       | –                               | –                        | –              | –                        | –            |
| I do not know                   | 0                       | 0                               | 0                        | 0              | 0                        | 5            |

a Sixty-seven participants were eligible to respond to those questions (parents who had a child who currently uses a standing frame). Total does not equal 67 as there were missing data.

**TABLE 6** Parent report of duration of prescribed and actual standing frame use

| Prescribed use <sup>a</sup>                                    | Actual use <sup>a</sup> |           |               |                      |   |              |
|--|-------------------------|-----------|---------------|----------------------|---|--------------|
|  | > 2 hours               | 1–2 hours | 30–60 minutes | Less than 30 minutes | Not recommended in this location (home or school) | Did not know |
| > 2 hours  | 0                       | 0         | 0             | 0                    | 0   | 0            |
| 1–2 hours  | 0                       | 3         | 2             | 1                    | 0   | 0            |
| 30–60 minutes  | 0                       | 1         | 23            | 0                    | 0   | 0            |
| < 30 minutes   | 0                       | 0         | 0             | 5                    | 0   | 1            |
| Not recommended in this location <sup>b</sup> (home or school) | 0                       | 0         | 0             | 0                    | 3   | 0            |
| Did not know   | 0                       | 0         | 1             | 0                    | 0   | 7            |

a Sixty-seven participants were eligible to respond to those questions (parents who had a child who currently uses a standing frame). Total does not equal 67 as there were missing data.

b This question asked about standing frame use in different locations, and parents could indicate if particular locations were not relevant (e.g. a standing frame may be used at school but not prescribed for home use).

Professionals considered a variety of factors, including physical space and cost, when choosing standing frames. They generally considered starting standing frame use by 18 months of age (*Table 7*).

Most professionals and parents reported waiting times for standing frames to be up to 13 weeks from identification of need to commencing a standing frame programme (*Table 8*).

**TABLE 7** Professionals' choices about standing frames

| Factors  | Prescribing clinicians,<br><i>n</i> (%) | Non-prescribing professionals,<br><i>n</i> (%) |
|--|---|--|
| External factors influencing choice of standing frame              |   |  |
| Physical space   | 225 (73.8)                              | 88 (56.8)                                      |
| Cost of standing frames or funding pathways                        | 214 (70.2)                              | 96 (61.9)                                      |
| Availability of standing frames                                    | 206 (67.5)                              | 87 (56.1)                                      |
| Parent or young person choice of standing frame                    | 163 (53.4)                              | 63 (40.6)                                      |
| Other  | 45 (14.7)                               | 22 (14.2)                                      |
| Missing  | 19 (6.2)                                | 20 (12.9)                                      |
| Age at which they would first consider starting standing frame use |   |  |
| < 6 months   | 1 (0.3)                                 | 4 (2.6)  |
| 7–12 months  | 75 (24.6)                               | 29 (18.7)                                      |
| 13–18 months   | 171 (56.1)                              | 57 (36.8)                                      |
| 19–24 months   | 34 (11.1)                               | 29 (18.7)                                      |
| 25–30 months   | 4 (1.3)                                 | 9 (5.8)  |
| > 30 months  | 5 (1.6)                                 | 10 (6.5)                                       |
| Missing  | 15 (4.9)                                | 17 (11)  |

Percentages > 100% because participants could choose more than one option.

**TABLE 8** Standing frame waiting times as described by prescribing clinicians, non-prescribing professionals and parents

| Average waiting time | Prescribing clinicians, <i>n</i> (%) | Non-prescribing professionals, <i>n</i> (%) | Parents, <i>n</i> (%) |
|----------------------|--------------------------------------|---|-----------------------|
| < 4 weeks            | 23 (7.5)                             | 3 (1.9)                                     | 16 (17.6)             |
| 4–8 weeks            | 106 (34.8)                           | 25 (16.1)                                   | 25 (27.5)             |
| 9–13 weeks           | 86 (28.2)                            | 18 (11.6)                                   | 12 (13.2)             |
| 14–20 weeks          | 29 (9.5)                             | 10 (6.5)                                    | 5 (5.5)               |
| 21–25 weeks          | 5 (1.6)                              | 1 (0.6)                                     | 2 (2.2)               |
| > 26 weeks           | 2 (0.7)                              | 0   | 5 (5.5)               |
| Did not know         | 38 (12.5)                            | 82 (52.9)                                   | 15 (16.5)             |
| Missing              | 16 (5.2)                             | 16 (10.3)                                   | 11 (12.1)             |

Tables 9 and 10 show that most prescribing clinicians suggested that standing frame use should be monitored (for suitability of the standing frame) and reviewed (for the suitability of the standing frame programme) every 3 months or more often.

**TABLE 9** Prescribing clinicians' routine monitoring of the suitability of the standing frame for the young person, ideally and in practice

| Monitoring: ideal                                    | Monitoring: in practice |        |             |         |                            |                  |                |
|--|-------------------------|--------|-------------|---------|----------------------------|------------------|----------------|
|  | More than once per week | Weekly | Fortnightly | Monthly | Every 3 months (or termly) | Less than termly | When requested |
| More than once per week                              | 3                       | 1      | 0           | 0       | 0                          | 0                | 0              |
| Weekly   | 1                       | 7      | 2           | 13      | 8                          | 0                | 1              |
| Fortnightly  | 0                       | 0      | 1           | 5       | 9                          | 0                | 0              |
| Monthly  | 0                       | 0      | 0           | 19      | 68                         | 3                | 9              |
| Every 3 months (or termly)                           | 0                       | 0      | 0           | 1       | 65                         | 30               | 20             |
| Less than termly                                     | 0                       | 0      | 0           | 0       | 1                          | 6                | 0              |
| When requested                                       | 0                       | 0      | 0           | 0       | 1                          | 1                | 3              |
| <b>Note</b><br>A total of 27 responses were missing. |                         |        |             |         |                            |                  |                |

**TABLE 10** Prescribing clinicians' reviewing of the standing frame programme for the young person, ideally and in practice

| Reviewing: ideal                                     | Reviewing: in practice  |        |             |         |                            |                  |                |
|--|-------------------------|--------|-------------|---------|----------------------------|------------------|----------------|
|  | More than once per week | Weekly | Fortnightly | Monthly | Every 3 months (or termly) | Less than termly | When requested |
| More than once per week                              | 1                       | 0      | 0           | 1       | 0                          | 0                | 0              |
| Weekly   | 1                       | 5      | 0           | 5       | 2                          | 0                | 1              |
| Fortnightly  | 0                       | 0      | 2           | 8       | 3                          | 0                | 1              |
| Monthly  | 0                       | 0      | 0           | 14      | 62                         | 6                | 5              |
| Every 3 months (or termly)                           | 0                       | 0      | 0           | 3       | 86                         | 31               | 19             |
| Less than termly                                     | 0                       | 0      | 0           | 0       | 0                          | 8                | 2              |
| When requested                                       | 0                       | 0      | 0           | 1       | 0                          | 1                | 8              |
| <b>Note</b><br>A total of 29 responses were missing. |                         |        |             |         |                            |                  |                |

### **Reasons for use, and perceived benefits and difficulties associated with standing frames**

Parents reported all the benefits they observed for their child, including opportunities for a change of position, participation and enjoyment in activities, and interaction with peers (*Table 11*). Eighty-nine per cent of parents reported more than one benefit. When parents were asked to indicate the three most important benefits of standing frames, the most frequently selected choice was the opportunity for a change of position, second was a reduced risk of hip dislocation or damage, and equal third were improvement of bladder and bowel function and a reduced risk of joint contractures (see *Table 15*).

**TABLE 11** Parents' perceptions of the benefits of standing frames

| Benefits of standing frame use   | Parent-reported benefits for their child, <i>n</i> (%) |
|--|--|
| Enjoy activities   | 39 (42.9)  |
| Help child communicate   | 12 (13.2)  |
| Help child stand independently in future                                   | 29 (31.9)  |
| Help child use their vision  | 21 (23.1)  |
| Help child walk in future  | 17 (18.7)  |
| Improve bladder and bowel functions  | 52 (57.1)  |
| Improve bone density/strength  | 56 (61.5)  |
| Improve breathing  | 25 (27.5)  |
| Improve motor abilities (head control)                                     | 34 (37.4)  |
| Improve motor abilities (trunk control)                                    | 45 (49.5)  |
| Improve motor abilities (upper limbs)                                      | 40 (44)  |
| Interact with peers  | 42 (46.2)  |
| Opportunity for a change of position                                       | 72 (79.1)  |
| Participate in activities  | 52 (57.1)  |
| Reduce risk of fractures   | 23 (25.3)  |
| Reduce risk of hip dislocation or damage                                   | 47 (51.6)  |
| Reduce risk of joint contractures  | 52 (57.1)  |
| Percentages > 100% because participants could choose more than one option. |  |

Prescribing clinicians and non-prescribing professionals consistently reported that they used the frames to offer the young person a change of position; improve BMD, breathing, bladder and bowel functions; reduce the risk of fractures and joint contractures; reduce the risk of hip dislocation or damage; and improve motor abilities, communication, vision, activity enjoyment, participation in activities and peer interaction (*Table 12*).

Both prescribing clinicians and non-prescribing professionals reported that as well as child-specific factors, environmental and personal factors, such as cost, space for use and storage, availability of frames and parent/young person's choice of frame also determined the most appropriate standing frame to use.

*Tables 13 and 14* outline the difficulties that prescribing clinicians, non-prescribing professionals and parents experienced with the prescription and use of standing frames. Resourcing and environmental factors included funding for frames (87% of non-prescribing professionals), physical space in the home (78% of prescribing clinicians) and a child having a standing frame at nursery/school but not at home (55% of parents). Child-specific factors as identified by the respondents included needing a rest from using a frame (25.3%), dislike of using a standing frame (19.8%) and experiencing pain (14.3%). These were more frequently reported by parents of children who no longer used frames (31.6% of parents of previous users reported pain compared with 10.4% of parents of current users).

**TABLE 12** A comparison of professionals' rationales for prescribing standing frames

| Benefits                                 | Patient age (years), n (%)          |                               |                                     |                               |                                     |                               |
|--|-------------------------------------|-------------------------------|-------------------------------------|-------------------------------|-------------------------------------|-------------------------------|
|  | < 5                                 |                               | 5–11                                |                               | 12–18                               |                               |
|  | Prescribing clinicians <sup>a</sup> | Non-prescribing professionals | Prescribing clinicians <sup>a</sup> | Non-prescribing professionals | Prescribing clinicians <sup>a</sup> | Non-prescribing professionals |
| Enjoy activities                         | 231 (75.7)                          | 77 (49.7)                     | 230 (75.4)                          | 79 (51)                       | 222 (72.8)                          | 77 (49.7)                     |
| Help child communicate                   | 217 (71.1)                          | 68 (43.9)                     | 217 (71.1)                          | 67 (43.2)                     | 212 (69.5)                          | 67 (43.2)                     |
| Help child stand independently in future | 59 (19.3)                           | 46 (29.7)                     | 96 (31.5)                           | 36 (23.2)                     | 55 (18)                             | 23 (14.8)                     |
| Help child to use their vision           | 173 (56.7)                          | 58 (37.4)                     | 170 (55.7)                          | 56 (36.1)                     | 169 (55.4)                          | 54 (34.8)                     |
| Help child walk in future                | 120 (39.3)                          | 29 (18.7)                     | 77 (25.2)                           | 22 (14.2)                     | 38 (12.5)                           | 15 (9.7)                      |
| Improve bladder and bowel function       | 225 (73.8)                          | 66 (42.6)                     | 231 (75.7)                          | 69 (44.59)                    | 229 (75.1)                          | 65 (41.9)                     |
| Improve bone density/strength            | 217 (71.1)                          | 70 (45.2)                     | 224 (73.4)                          | 71 (45.8)                     | 208 (68.2)                          | 64 (41.3)                     |
| Improve breathing                        | 205 (67.2)                          | 59 (38.1)                     | 207 (67.9)                          | 61 (39.4)                     | 208 (68.2)                          | 60 (38.7)                     |
| Improve motor abilities (head control)   | 243 (79.7)                          | 74 (47.7)                     | 234 (76.7)                          | 75 (48.4)                     | 196 (64.3)                          | 64 (41.3)                     |
| Improve motor abilities (trunk control)  | 221 (72.5)                          | 60 (38.7)                     | 217 (71.1)                          | 62 (40)                       | 176 (57.7)                          | 54 (34.8)                     |
| Improve motor abilities (upper limbs)    | 226 (74.1)                          | 70 (45.2)                     | 222 (72.8)                          | 72 (46.5)                     | 201 (65.9)                          | 62 (40)                       |
| Interact with peers                      | 238 (78)                            | 75 (48.4)                     | 239 (78.4)                          | 76 (49)                       | 233 (76.4)                          | 73 (47.1)                     |
| Opportunity for a change of position     | 245 (80.3)                          | 81 (52.3)                     | 246 (80.7)                          | 82 (51.6)                     | 244 (80)                            | 81 (52.3)                     |
| Participate in activities                | 243 (79.7)                          | 79 (51)                       | 242 (79.3)                          | 81 (52.3)                     | 238 (78)                            | 79 (51)                       |
| Reduce risk of fractures                 | 175 (57.4)                          | 47 (30.3)                     | 175 (57.4)                          | 51 (32.9)                     | 172 (56.4)                          | 52 (33.5)                     |
| Reduce risk of hip dislocation or damage | 225 (73.8)                          | 60 (38.7)                     | 219 (71.8)                          | 63 (40.6)                     | 195 (63.9)                          | 56 (36.1)                     |
| Reduce risk of joint contractures        | 234 (76.7)                          | 67 (43.2)                     | 237 (77.7)                          | 72 (46.5)                     | 232 (76.1)                          | 69 (44.5)                     |

<sup>a</sup> Responses of non-prescribing and prescribing clinicians refer to indications of standing frame use for GMFCS IV and/or V. Percentages add up to more than 100% because participants could choose more than one option.

**TABLE 13** Difficulties associated with prescription and use of standing frames as identified by professionals

| Difficulties identified by professionals                                   | Prescribing clinicians, <i>n</i> (%) | Non-prescribing professionals, <i>n</i> (%) |
|--|--------------------------------------|---|
| Resources  |                                      |   |
| Allocation of resources or funding for frame                               | 183 (60)                             | 89 (87.4)                                   |
| Allocation of resources for staff to prescribe/monitor use                 | 64 (21)                              | 42 (27.1)                                   |
| Availability of parents/carers at home to help position the child          | 166 (54.4)                           | 74 (47.7)                                   |
| Availability of staff/carers in school to help position the child          | 176 (57.7)                           | 72 (46.5)                                   |
| Environment  |                                      |   |
| Physical space at home   | 238 (78)                             | 96 (61.9)                                   |
| Physical space at school   | 124 (40.7)                           | 53 (34.2)                                   |
| Transportation of equipment  | 106 (34.8)                           | 55 (35.5)                                   |
| Other  | 62 (20.3)                            | 26 (16.8)                                   |
| Percentages > 100% because participants could choose more than one option. |                                      |   |

**TABLE 14** Difficulties associated with prescription and use of standing frames as identified by parents

| Difficulties identified by parents  | Parents (previous users and current users at home only), <sup>a</sup> <i>n</i> (%) | Parents (current users but not at home), <sup>b</sup> <i>n</i> (%) |
|---|--|--|
| Resources   |  |  |
| Time  | 25 (48.1)  | 4 (12.1)   |
| Do not have a standing frame at home  | –  | 18 (54.6)  |
| Using a standing frame at home was not recommended  | –  | 2 (6.1)  |
| Availability of parents/carers to help position the child   | 14 (26.9)  | 9 (27.3)   |
| Environment   |  |  |
| Physical space  | 19 (36.5)  | 16 (48.5)  |
| Sometimes moving and handling difficulties at home for child  | 14 (26.9)  | 6 (18.2)   |
| Difficulty with access to other equipment used to position child in the frame   | 10 (19.2)  | 3 (9.1)  |
| Child factors   |  |  |
| Child dislikes standing in their frame  | 14 (26.9)  | 4 (12.1)   |
| Child sometimes wants a rest from using the frame   | 19 (36.5)  | 4 (12.1)   |
| Child experiences pain when standing in their frame   | 12 (23.1)  | 1 (3)  |
| Other   | 7 (13.5)   | 6 (18.2)   |
| <p><sup>a</sup> Percentages were calculated out of a total of 52 because this is the number of participants who were eligible to respond to those questions and provided an answer [parents who had a child who currently uses a standing frame (only outside the home) did not answer this question].</p> <p><sup>b</sup> Percentages were calculated out of a total of 33 because this the number of participants who were eligible to respond to those questions and provided an answer [only parents who had a child who currently uses a standing frame (but do not use it at home) answered this question].</p> <p>Percentages &gt; 100% because participants could choose more than one option.</p> <p>‘–’ indicates that the item was not a response option for that group of participants.</p> |  |  |



## What did survey 1 add?

Survey 1 provided insight into current standing frame use. Standing frames were widely used as part of postural management for young people with CP, despite limited evidence of clinical effectiveness. Prescribing practice was generally consistent across the UK, but achieving the prescribed use was not always possible because of resources or environment/child factors. Professionals and parents of young people with CP were invested in using standing frames. They reported a variety of benefits, although they also recognised many challenges associated with standing frame use.

## How did survey 1 inform the next step?

Survey 1 was primarily used to inform the content in the next stages of the Understanding Frames study; that is, single stakeholder focus groups, interviews and multistakeholder focus groups. For example, survey 1 gave the research team insight into the perceived benefits of standing frames. However, it was unclear which benefits were research priorities for different stakeholder groups. There were also specific topics and/or issues raised in survey 1 that were necessary to explore with particular stakeholder groups, and these are outlined here.

The large number of physiotherapist respondents in survey 1 demonstrated that they are a key stakeholder group with an interest and investment in standing frames. This led to the following topics for exploration: whether or not physiotherapists are prepared to recruit to a trial, their anticipated barriers to trial recruitment and what kind of outcomes that they believe would be appropriate to use to examine the clinical effectiveness of standing frames. In terms of education professionals, we wanted to explore which of the challenges identified in survey 1 were specific to the classroom. We also asked for their opinions on adherence to a standing frame prescription, and how they would feel if they could not meet such requirements for the purposes of a trial. For parents, survey 1 revealed that many older young people were not using a standing frame, particularly during the school holidays. We needed to explore whether or not suspending standing frame use for this amount of time for the purposes of a trial (or switching standing frame use for an appropriate comparator) would be acceptable to parents. We explored all of these issues in the qualitative stages of the study.

Finally, participants in survey 1 provided contact details if they wished to participate in further stages of the Understanding Frames study (e.g. focus groups). Parents also provided contact details if their child was interested in being interviewed. Therefore, survey 1 was vital for participant recruitment for the later stages of the study.



## Chapter 4 First stage focus groups: single stakeholder

### Objectives

Five single stakeholder focus groups were held to explore views on the design and challenges of a trial to determine the clinical effectiveness of standing frame use in young people with CP.

### Methods

#### Population

Single stakeholder focus groups were conducted with the same populations as survey 1; that is, clinicians, physiotherapists, education staff and parents. Respondents to survey 1 provided their contact details if they were willing to take part in other stages of the research. From this, a shortlist of potential participants was created for each group to ensure a representative sample. Potential participants were contacted via telephone or e-mail (depending on the contact details they provided in survey 1); the study was explained, and if the person was interested an information sheet and invitation to attend the appropriate focus group were posted or e-mailed to them, depending on preference.

#### Topic guide development and conduct of focus groups

A meeting was held with co-applicants Jill Cadwgan, Jan Lecouturier, Johanna Smith and research associate Jane Goodwin to discuss how the survey 1 results should inform the topic guide, and which topics should be explored. It was agreed that information on the context (e.g. purpose of study, findings from our study so far) would be helpful. Rather than rely on attendees reading materials sent beforehand, it was decided to give a presentation [Microsoft PowerPoint® (Microsoft Corporation, Redmond, WA, USA) Presentation Manager 2013] about the study, the current evidence base and the results from our study so far. In addition, it was deemed important to explain levels of evidence and elements of trial design (i.e. PICOTS framework). Furthermore, it was suggested that we give participants time to introduce themselves, especially parents, so that there would be an informal, friendly start to the conversation with everyone given equal status. We chose a few topics to explore in detail with the aim of stimulating rich, thoughtful discussion. The topics were chosen to clarify the findings from survey 1 (e.g. why was an opportunity for change of position a benefit of standing frames?) and increase our understanding of research feasibility (e.g. would school or home be a better setting for a research trial?).

Following the meeting, there was an e-mail conversation with the wider team, and informal discussions with PPI members, as well as parents and health professionals known to the co-applicant team, were conducted. Minor adjustments were made as a result of these conversations, such as reducing the amount of information on the PowerPoint slides. We were also mindful that participants may have invested in standing frames and may not be aware that there is limited evidence for their use, and sought to handle this sensitively. The facilitators for each focus group were also decided at this stage. Each focus group had a lead facilitator and co-facilitator, at least one of whom was a qualitative researcher (JL or JG). The second facilitator was selected depending on background and logistics.

The final topic guide included (1) opinions on survey 1 results, (2) perceived benefits of standing frames, (3) challenges associated with standing frame use and (4) feasibility aspect of a future trial (see *Appendix 4*). Minor amendments were made to the topic guide for each group, which evolved iteratively. For example, we asked education staff about their experiences of how young people 'perform' in a standing frame at school, and we asked parents how they felt on learning that there is limited evidence for standing frame use.

The brief PowerPoint presentation given at the beginning of the focus group, which informed the participants and framed the discussion around pertinent issues, is provided in *Appendix 5*.

### **Procedure**

Five single stakeholder focus groups were conducted, with one each for physiotherapists, medical professionals and education professionals, and two for parents. One group was held for parents residing in the north and one in the south of England to ensure that we captured any geographical variation while minimising travel burden for parents.

The process of contacting and recruiting participants was identical for each of the focus groups. Potential participants were contacted via telephone or e-mail to explain the study, then an information sheet was e-mailed or posted out to them if they expressed an interest. Written consent was obtained on the day of the focus groups, before discussion commenced. Focus groups were digitally recorded with the permission of the participants. Sound files were transcribed verbatim and anonymised.

## **Findings**

### **Participants**

Five focus groups were convened in June and July 2016: two with parents of young people with CP (one in the North and one in the South), one with physiotherapists from around the UK (including London, Newcastle, Leeds, Leicester and Liverpool) who worked in a variety of services, one with clinicians (in the West Midlands) and one with education staff from a specialist school (in the North East). The numbers attending the groups ranged from three to nine. The numbers in one of the parent groups and the clinician group were lower than anticipated, three and five respectively, but the data were rich and all attendees participated fully in the discussion. It is important to note that because of difficulty in recruiting non-prescribing clinicians, two members of the research team (AR and KM) participated in the clinician focus group. Therefore, caution must be taken when interpreting the results, and we have indicated which quotes were from members of the research team.

### **Focus group format**

Focus groups were scheduled for two hours including breaks. Refreshments were provided at each group. As a gesture of goodwill, attendees were offered a £10 Amazon voucher (Amazon.com, Inc., Bellevue, WA, USA). At the beginning, the study information sheet was provided to each attendee and they were given time to read through it. Written consent was obtained and ground rules agreed. Before the discussion, and to set the scene, a member of the research team gave a 10-minute PowerPoint® presentation. This presentation covered background information around the levels of evidence on which clinical decisions are made and the evidence base for standing frame use, results from the Understanding Frames survey <sup>124</sup> (see *Chapter 3*), the purpose of the focus groups and the topic questions.

### **Perceived benefits of standing frame use and potential outcomes for a trial**

Participants in survey 1 had been asked to identify the three most important benefits of standing frame use. We then ranked these based on frequency (*Table 15*) and presented them on the screen, and a member of the research team summarised these verbally. The aims were to generate discussion, elicit attendees' views on these perceived benefits and ascertain what would be useful and meaningful to measure to determine the outcome of standing frame use.

### **Opportunity for a change of position**

As illustrated in *Chapter 3*, 'change of position' was one of the most commonly mentioned benefits of standing frame use cited in survey 1. As there was no opportunity in the survey to elicit why a change of position was a benefit, this was explored in the groups. Two main reasons were given by parents,

**TABLE 15** Ranked benefits from the findings of survey 1

| Rank | Benefit                                  |
|------|--|
| 1    | Opportunity for a change of position     |
| 2    | Reduce risk of hip dislocation or damage |
| = 3  | Reduce risk of joint contractures        |
| = 3  | Improve bladder and bowel function       |
| 5    | Improve bone density/strength            |
| 6    | Enjoy activities                         |
| 7    | Interact with peers                      |
| 8    | Participate in activities                |
| 9    | Help child stand independently in future |
| 10   | Improve motor abilities (trunk control)  |
| 11   | Improve motor abilities (upper limbs)    |
| 12   | Help child walk in future                |
| 13   | Improve motor abilities (head control)   |
| 14   | Improve breathing                        |
| 15   | Help child use their vision              |
| 16   | Help child communicate                   |
| 17   | Reduce risk of fractures                 |

physiotherapists and education staff. The first was that it supports social interactions and enables the child to be able to see what is happening at a different level:

*It was a social thing . . . he had a lot of young friends in the community who used to come in and I think being able to stand when they were standing as well, it was good for him to be at a similar height.*

*Parent group*

*From the educational point of view what is often forgotten about is if you find a different position your perspective on the world and how you feel about the world and what you see . . . is totally different . . . as soon as you put them in a standing frame you've changed that so they are going to get a totally different feedback . . . about their environment, about everything.*

*Education staff group*

In the clinician group there was recognition of the importance of standing frames in facilitating social interaction but also that, depending on the situation, this could be isolating for children:

*Because the point about social interaction, I think it's all very well if you're in a standing frame but if you're static in the classroom with all the other kids running around, you're not socially interacting.*

*Clinician group*

This was also raised in the physiotherapist group, and one attendee said they had overcome this problem by having a number of children using standing frames at the same time to form a group. However, the education staff group, which was from one specialist school, commented that in their school there were too few standing frames to have one per child, limiting the number who could be standing at the same time.

The physiotherapist group recognised the importance of participation and commented that there sometimes had to be a trade-off between participation and maintaining body structure and body function. They commented that standing can improve participation in the classroom for some children, particularly those who use assistive technology such as switches. An example was given of one child who communicated to the physiotherapist that she felt more alert in the classroom when standing. Education staff were of the same opinion, and talked of children who were more involved in group discussions when standing, and could participate in classroom activities such as arts and crafts. The physiotherapist group thought that some children had better head control when standing, which could facilitate participation in certain classroom tasks or subjects.

On a less positive note, education staff were also aware of children whose participation was restricted when standing. For example, when using a communication aid, such as a voice output communication aid (VOCA), there were problems situating the device at the child's eye level. They also believed that some children are not comfortable when standing, either because it is painful or unfamiliar to them:

*If you put them in a stander you know they're not going to perform because they are so concerned over how they feel because they are not used to being in those positions . . . it overrides everything and they can't actually focus on anything else.*

*Education staff group*

The second reason for the importance in a change of position was to give the young person the opportunity to stretch out after being in a sitting position for sometimes up to 10 hours a day; standing was thought to combat stiffness. Parents considered how they themselves would feel being restricted to a sitting position for hours on end and that 'most people wouldn't be able to tolerate it at all'. For one parent, the standing frame achieved both perceived benefits of a change of position:

*We usually have the choice of either his wheelchair or his bed. So to keep him in the living room and keep him with everybody else where everything is going on, transfer him to a standing frame and allow him to have a bit of a stretch out and still be with everybody.*

*Parent group*

For those in the education staff group, standing fulfilled the need for the children to stretch their muscles, particularly the hamstrings, and reduce the risk of contractures. They commented that, with some children, they could see a deterioration in skills (e.g. posture, joint range of movement) and an increase in stiffness when they had not been using a standing frame.

Parents said a change of position led to something tangible where they could 'see the relief in a change of position' whereas other 'clinical' effects were not easy for them to recognise. For this and the other reasons mentioned, a change of position was considered very important for the majority of parents.

### **Improve bladder and bowel function**

Most parents also supported the survey result of standing frames being beneficial to digestion and bowel function, and reported that not using a frame had an impact on bowel movement. This was evidenced by parents who noticed a difference in the school breaks or following surgery when their child did not use a standing frame:

*I know for a fact if he doesn't stand his bowels do block up.*

*Parent group*

The use of a standing frame to encourage bowel movements was also mentioned in the physiotherapist and education staff focus groups. The latter said some children stand during or following lunch to aid

digestion. The physiotherapist group commented that, for the older children in particular, this was the main purpose of using a standing frame:

*We have children who remain medication free and better managed by their families because of that reason. And they say if the child doesn't stand then they have to use medication and that makes it very difficult to manage the bowels and makes it harder for them to go out.*

*Physiotherapist group*

### Improve bone mineral density and reduce risk of contractures

In the clinician group there was a discussion about the potential of standing frames in improving bone strength and reducing the risk of contractures. BMD was considered to be a surrogate measure of benefit but if the child 'does not have an increased rate of fractures, what does it matter?'. One parent attributed improved bone density to using a standing frame but another parent commented that a trial where this was the main measure of effect may not be appealing to parents:

*When my son had his hip operation, they said that his bone density was really good therefore the operation was a lot . . . there was a good fix with the pins and stuff. I think had he not used the standing frame, they wouldn't have been as strong.*

*Parent group*

*I think you'd need a list . . . rather than just one specific thing. Because I think if it was just bone density . . . I don't know how eager I would have been to put him in it and go through that every day when he was younger I think you need to have all the potential benefits to weigh up.*

*Parent group*

Physiotherapists commented that measuring bone density would not be appropriate in children who use supine boards rather than standing frames, as they are not weight bearing. Another raised the issue of which bone to measure, and referred to a study where time in a standing frame was doubled but the team did not measure bone density in the femur: 'I'm sure if they'd have got different results if they'd measured the femur instead'. In the clinician group it was thought that a longitudinal study would be needed to measure the impact of standing on BMD; to date only short-term studies have been conducted using this as an outcome.

In terms of reducing the risk of contractures, there were mixed feelings in the clinician group about whether or not this was important in determining the impact of standing frames. One person thought that if a child uses a wheelchair all of the time, then reducing the risk of contractures was not as important. There was an alternative view from another in the group which said that pain from contractures was an important issue; interestingly, pain reduction was not included as a benefit of standing frames in the responses to survey 1. As well as stressing the importance of reducing pain, the group also concurred with what was said by physiotherapists, namely that there should be a consideration of what happens to children in later life:

*Standing is a physiological need of the body, it's not a luxury – long-term pain and contractures do have . . . a knock-on effect on the rest of the joint . . . long term they may have the effect in their adulthood as an result of not doing the physiotherapy and the stretching early on.*

*Clinician group*

This person went on to say that if a child is compliant with standing frame use 'the outcomes that we see are completely different in terms of contractures and pain'. It was felt in the clinician group that it could be possible to measure a change in contractures in a 12-month period.

### Improve motor abilities – trunk, head and upper limbs

The physiotherapist group raised the issue of maintaining movement and mobility of the joints because of the 'unknowns' for these children as they grow. They commented on pain, which was also mentioned as an important factor by the clinician group:

*I think it's a pain factor and I wonder whether it's important to maintain a range of movement and some sort of mobility for all the joints because as they transition into adulthood . . . the debilitating factor is the pain.*

*Physiotherapist group*

Physiotherapists also believed that maintaining alignment of the trunk and pelvis was important for respiratory function and preventing scoliosis. Parents and education staff mentioned the benefits of standing frames in relation to posture:

*His core stability is really bad so he leans all the time which I think is making his scoliosis worse as well. Whereas he hasn't got as much pressure through his back if he's in a stander.*

*Parent group*

Education staff gave an example of the difference a standing frame was making for one child by enabling her to achieve and maintain a straight position while in her wheelchair:

*We have one [child] who only recently started going in [standing frame] every morning . . . we're at 45 minutes of standing, to keep the head up and straighten up and you can't half see the difference. . . . It's working for her.*

*Education staff group*

### Prevention or delay of surgical intervention

The potential for standing frames to prevent or delay surgical intervention was a perceived benefit mentioned by physiotherapists and parents that had not been reported as a finding from survey 1. For physiotherapists, using a standing frame to prevent surgery would depend on the child's gross motor function:

*We use standing frames a lot with GMFCS V to maintain and prevent surgery and try and give them that prolonged stretch that we can't necessarily do in other positions, whereas then we have GMFCS II who we would use to try and increase lower limb strength or try to build up the function.*

*Physiotherapist group*

Another commented that they use standing frames primarily to provide a change of position but perhaps in the back of their mind to prevent surgery:

*And I kind of think, well I'm not sure but I'd use it to kind of help prevent hip surgery but I don't know whether it does long term or not because I've had a few kids who have refused to use standing frames and use their walkers instead and they're still doing okay without needing surgery.*

*Physiotherapist group*

A number of parents said their child had undergone surgery despite using a standing frame. There was a discussion and a belief that their children would have needed surgery regardless, but that use of the standing frame had delayed it. Despite the fact that the standing frame did not prevent surgery, one parent said there had been other benefits. Another parent, whose child used a walker and needed hip



surgery, said, 'I do not know if that's down to me not having a standing frame at home'. A suggestion was made by the parent group for a study to determine the impact of surgery:

*So if you can get X-rays [radiographs] from young babies who are likely to have cerebral palsy or mobility issues, then you'll be able to watch the hip X-rays [radiographs] and see whether that's making any difference and whether it changes the outcome of them having to have major hip surgery or not.*

*Parent group*

This reflects the point made by the clinician group that hip dislocation would be difficult as an outcome measure because of the length of time in which children would have to be followed up. Clinicians also added that the pathology was little understood and there were a number of confounding variables.

### Reduce risk of pressure sores

One parent commented that as children with CP tend to be very thin there is an increased risk of pressure sores from sitting, and standing reduces that risk. The education staff focus group also mentioned that a long time spent in a wheelchair can become uncomfortable for children and the opportunity to stand is a relief for them and 'takes the pressure off their bottoms'.

### Other benefits

Other benefits of standing frames mentioned were improved respiratory function (particularly an improvement in breathing), helping the child to relax (as they have more support in a standing frame than in a wheelchair), and reduced spasms. Parent participants also felt emotional seeing their non-ambulant child in a standing position. These feelings were still very strong, even years later, with participants becoming teary while discussing it.

### *What should the trial intervention and comparator be?*

In the presentation to the groups the following examples were given of interventions and comparators: delayed or suspended use of a standing frame, a comparison of other devices, or therapies.

### Current standing frame versus no standing frame use

#### *Delayed start*

The question was posed, would parents have taken part in a trial in which the introduction of a standing frame was delayed by 6 months? Clinicians had reservations about the ability to recruit to such a study and commented that most parents would feel that their child was missing out on a potentially beneficial therapy. One of the physiotherapists thought that a waiting list control of delayed standing frame introduction would be an acceptable study design, but then added that they were unsure whether or not this was ethical. When broached with parents, this option was not popular, despite accounts of delays of months in obtaining a standing frame when their child was first prescribed one, and the lack of evidence for their clinical effectiveness:

*I can see why it would be useful in a study, but I wouldn't want to be in the group that didn't [get it].*

*Parent group*

*You'd go out of your way to get it if you thought it was going to make any difference at all and I don't think I'd want to be a parent in the 'wait and see group' if I thought there was something there that could help.*

*Parent group*

The reason for this parental stance was that, even in the face of a lack of evidence of clinical effectiveness, parents want to ensure that they have tried everything that may benefit their child; they would feel that they were missing out in a 'delayed use' trial design. Parents mentioned they would feel guilty if they delayed the introduction of anything that may help:

*... it would always be in the back of your head that if they had been in it sooner would it have made any difference.*

*Parent group*

Some commented that it would be unlikely that parents would be happy to participate if they had to delay the intervention onset, particularly as it would be around the same time as receiving their child's diagnosis of CP. Only one parent disagreed:

*You see I would have done. My daughter, she was 9 months old before she was diagnosed and ... I saw the standing frames in a line and they looked like pieces of torture equipment ... so if they'd given me a choice I'd have said no.*

*Parent group*

This parent said she had not been aware of the lack of evidence of the benefits of standing frames at that time. One parent in the other group felt that an awareness of the rationale for, and the benefits of, standing frame use would 'give the parent more of an understanding of whether they would want to take part in something like that or not'.

Even when an alternative therapy was suggested for the delayed standing frame group, opposition to the idea remained in the parent group. However, one parent said that it would depend on the alternative therapy and mentioned their experience of having physiotherapy 'with a lot of standing' when her child was younger. In the other parent group, hydrotherapy was mentioned as an alternative and this appeared to have the approval of the other parents.

### ***Suspended standing frame use***

Withdrawal of the standing frame was not a popular option and the majority were uncomfortable with this as a trial design. It was not something clinicians or physiotherapists would feel happy to approach parents about and recruit children to. Education staff would be unhappy to deliver this type of intervention based on the belief that standing frames are beneficial:

*If you said, 'don't stand this student and stand that student to see if it's any different', because their overall health is obviously what's going to come first and we couldn't do that because of the implications of not standing ... and it would be too risky.*

*Education staff group*

A suggested option was to provide an alternative therapy rather than having nothing at all. In addition, to withdraw standing frame use would require the staff who prescribe them to communicate to parents and children the uncertainty around the benefits:

*It's difficult to do a comparison with no equipment whatsoever because lots of the equipment that we use has been used for years and years so how can we say 'we've suddenly decided it might not be useful anymore so we're just going to remove it' ... so I think you'd definitely have to compare one equipment versus another.*

*Physiotherapist group*

One other option identified would be to take advantage of the 'natural' breaks in the use of a standing frame. Parents suggested that, for example, bowel function and opportunity for change in position could be measured when children have surgical intervention. Another disruption in standing frame use for most

children is the school summer break (discussed below) and parents commented that when the children returned to school the physiotherapists knew whether or not they had been standing during the holiday:

*The first thing he'd say is . . . hasn't done any stretches. His legs would be crossed and they'd be bent.*  
Parent group

Fifteen other potential interventions were suggested (Table 16) across the five focus groups, with the current standing frame as a comparator. Some involved increased time in the current standing frame or additional therapies and others suggested different means of postural management. These are discussed in the following sections.

### **Increased time in standing frame per day**

The option of an intervention to compare two specified periods of time spent in a standing frame was raised spontaneously (i.e. without prompting from the facilitators) by the clinician focus group. This option was preferable to an intervention where one group of children would delay or stop using a standing frame for a certain period:

*There certainly will be an intervention where two identical children, one had an hour, one has half an hour and see what the difference is. So rather than none at all just reduce the amount of therapy. Would that provide an answer? I don't know.*

Clinician group – co-applicant KM

**TABLE 16** Suggestions for trial comparators and intervention

| Participant group  | Comparator   | Intervention                                 |
|--|--|--|
| Parents<br>Education staff<br>Physiotherapists<br>Clinicians     | Increased/reduced time in standing frame per day   | Standing frame use according to prescription |
| Parents<br>Physiotherapists<br>Clinicians                        | Use standing frame in summer holiday period/school breaks  |  |
| Parents<br>Education staff<br>Clinicians                         | No standing frame <sup>a</sup>   |  |
| Parents<br>Physiotherapists<br>Clinicians                        | Delayed start and other therapy  |  |
| Parents<br>Education staff                                       | New/different model of standing frame  |  |
| Parents<br>Education staff                                       | Other therapies (e.g. physiotherapy, botulinum toxin injections, stretching, massage rebound therapy)                    |  |
| Parents<br>Physiotherapists                                      | Powered/mobile standing frame  |  |
| Parents  | Standing frame plus physiotherapy<br>Hydrotherapy<br>Other equipment (e.g. seating systems, sleep systems, power chair)  |  |
| Physiotherapists   | Supine board<br>Night-time positioning<br>Sleep system<br>Abducted standing frame<br>Suspended standing – sling or hoist |  |
| Clinicians   | Contracture correction device  |  |
| a If there are regions where standing frames are not prescribed. |  |  |

Increased time spent in a standing frame compared with the standard prescribed time was a more popular option with the parent focus group, who thought that this would assuage any guilt parents may feel about delaying standing frame use. However, the issue of whether or not the child would be able to tolerate the recommended time was raised. Rather than a specified time, some in the parent focus group thought that a trial of frequency of standing frame use for a time that the child could tolerate may be more acceptable to parents:

*So you could say to a parent . . . 'You do once a day of your maximum toleration' and another parent, 'do twice a day at the maximum toleration'. I think that's the only way you could get the benefit of . . . a standing frame.*

*Parent group*

Although not raised as an intervention by the education staff group, they did comment that standing for 40 minutes 'must be uncomfortable'. They said that while some children do enjoy standing, particularly the pressure from being strapped in and held securely (also raised by the parent group), others do not. Some children are visibly tired at the end of the specified period. One also thought that certain children say it is painful as an excuse for being taken out of the standing frame:

*He just wants out. He doesn't like being in it so everything will hurt because he knows that that's a way of getting down.*

*Education staff group*

Other issues were raised about the feasibility of adhering to a prescribed frequency of standing. For example, parents mentioned that periods when the child is in hospital for surgery and is not able to stand as a result of this would interfere with such an intervention. In addition, one parent felt that not having the freedom to get their child into a standing frame when they thought that they had been sitting for too long would be a struggle for parents. Moreover, as another parent pointed out, when the standing frame is used to facilitate other functions a specified frequency of standing could be a problem:

*If [child] needed to open her bowels I'm not going to say, 'Oh she's been in this morning, I'm not going to put her in.' How would you control it? I'd have to put her in then say, 'She's been in twice today'.*

*Parent group*

Parents' focus was primarily on the practical implications of the proposed trial intervention occurring in the home setting. They commented that time (to lift and position the young person in the standing frame) was an issue, particularly when juggling other demands and with the need for 'several hands' to do it effectively. Another area of concern was lifting and handling with only one parent or carer present because of the risk of injury to the child and difficulty in attaining the correct positioning. Space was also an issue as many parents are unable to have a standing frame in the home because of its size. Some parents thought that this could have an impact on quality of life, particularly on the time they have available should they want to take their child out. It was also considered too burdensome and impractical for families:

*Prescribing to parents that [children] have to go in it this many times, actually that could be really hard. If someone's ill or something else has happened, I just think there are enough pressures on parents.*

*Parent group*

There was mention in the parent group that the trial could be conducted in a home setting with younger children (2–7 years of age), but recruiting parents to it could be problematic and they would have to fully understand the rationale for the study.

The parent group introduced the idea of conducting the intervention in a school setting because of these difficulties. However, the education staff group raised a number of problems with standing frame use in

schools. Apart from the shortage of equipment, there was the extra time and manpower required to get the child into the frame, which could interfere with class activity. In addition, there was the fact that the frame may have been adjusted to meet the needs of the last child who used it and would then need to be readjusted for the next user. Although not averse to the idea of running a trial in the school setting, education staff stressed there would have to be adequate support and resources in place to do so. Clinicians thought that teachers and teaching assistants may struggle to find the time to put a child in their standing frame, and that adherence to study protocol may be difficult.

### ***Standing frame use outside the school term***

Most parents said their child was not able to use a standing frame in the school summer break as they did not have the equipment at home. This period of non-use of standing frames was considered to cause problems with chest infections, bowel functions and returning to standing frame use when back to school. This view was shared by the physiotherapist group, who mentioned the difficulties of getting children back to using a frame. However, they thought that increased standing would only make a difference to a certain proportion of children with CP:

*For some children who are on a fine line of maintaining function – and we’ve all probably got them – that you just know that they’re going to go one way and then you’ll never get them back on [standing]. Those types of children I feel are the ones that 6 weeks without a standing frame . . . have secondary complications that cause a big effect.*

*Physiotherapist group*

One physiotherapist had experience of providing a standing frame for a child over the summer period and it was not used. The education staff group mentioned using the half term and/or six week summer break as an opportunity for children to continue to use a standing frame ‘if there was somewhere they could go to use a stander’ and ‘see the difference before and after summer’.

## **Current standing frame versus other equipment/therapies**

### ***Non-static standing***

Parents asked if the future trial could explore the impact or benefits of different types of standing frames rather than concentrate solely on the current standard in a delayed or increased frequency intervention. There was discussion around a non-static or motorised standing frame and the idea that this would make standing a more pleasurable experience and potentially improve compliance in standing:

*My son hated standing for a long time and we realised it was because we took him from his wheelchair that he could self-propel, put him in a standing frame where he couldn’t move so we were taking away his independence . . . So when we found a standing frame with big wheels he loves it. His default is now standing and he sits for his change of position. Sometimes I think that the whole culture needs to be changed. Who picked sitting as the standard?*

*Parent group*

Parents wondered if factors, such as boredom, rather than solely pain, may explain why children do not enjoy their time in a standing frame. One parent used videos to distract their child from the fact he was in a standing frame. Being able to control movement while in the standing frame was said to make them forget that ‘they are trussed up in a standing frame’. It was considered that this would make a difference to their children in terms of emotions, including their levels of happiness:

*You can actually get wheels for the EasyStand as well, or you can get the motorised ones. You can get different additions to it, which would obviously help with greater independence if they’re able to move around the home in a standing position because they can choose their own position.*

*Parent group*

Non-static standing frames or 'walkers' were also mentioned by physiotherapists when asked what other therapies could be compared with current standing frames in a future trial. One had experience of reviewing one of these with children in her care:

*I think walking frames would be a good comparison because then you're still getting the upright posture, you can still get quite a lot of support but then it's more of an active intervention rather than a passive stretch.*

*Physiotherapist group*

*A lot of the improvements were parents felt [the child had] looser bladder and bowels but the fun they had out of it was fantastic . . . it was wonderful seeing the child moving and the child loved it as well. So on that participation and function, on normality it was fantastic.*

*Physiotherapist group*

Non-static standing frames were also mentioned in the physiotherapist focus group when discussing the children's enjoyment of being in a standing frame. The group believed that mobile standing frames could enhance participation in a number of ways:

*It gives them more participation and it gives them more function and a bit of freedom and they can go around the playground with the others.*

*Physiotherapist group*

Clinicians also commented that, in contrast to a static standing frame where a child may feel isolated in the classroom, participation may be improved if children are in 'that sort of rabbit walker thing, yes, maybe you can engage more'. However, the cost of mobile standing frames was mentioned by both parents and physiotherapists as being prohibitive. Physiotherapists added that training in how to secure the child in the mobile standing frame would be required to ensure that they were safe.

### **Supine positioning**

Physiotherapists also discussed supine positioning as a comparator to static standing, but the choice of this within a trial context would depend on what outcome was being measured. They considered supine boards, which can be tilted from flat to upright, which would be suitable if the outcome of interest was trunk and pelvis alignment. This was felt to be important in maintaining the 'range of movements at the pelvis and the trunk in order to sit and function'. It was said also to help with respiratory function and as a way of stretching without standing. Supine positioning is suitable for children with poor head control whereas standing frames often are not:

*If you brought them from supine all the way up they wouldn't be able to lift their heads up. So they are children who are from say between 9 and 12, 13. They still get that benefit of stretching out and a couple of them really struggle to tolerate sitting for longer periods, they become really uncomfortable, so they like to come out.*

*Physiotherapist group*

Continuing with the discussion of maintaining alignment, hip integrity was thought by other physiotherapists in the group to be important, but with the end point being the prevention of surgical intervention. Night-time positioning and sleep systems were thought to help with hip integrity and were raised as other potential comparators to standing frames:

*There's an Acheeva® [Ledbury, UK] bed which is like a sleep system but you use it during the daytime and you can put an incline on it. You can use it prone or supine . . . though for some kids it doesn't hold their posture quite as firmly as a standing frame does.*

*Physiotherapist group*

The physiotherapists said they would be happy to recruit to this type of intervention and there was a discussion around whether or not this could be introduced in term time and then continued throughout the 6-week summer break. There was some anxiety around the withdrawal of standing frames for the group who would be randomised to supine positioning and it was stressed that it would have to be for a 'limited period'.

### **Other standing frames and therapies**

Abducted standing frames and suspended standing were also mentioned by physiotherapists. The former were said to have been around for years but do not appear to have been popular or commonly available among school equipment.

### **Target population in a trial of standing frame use**

Apart from clinicians, the general view across the stakeholder groups was that the target sample should be younger children, ideally aged around 2–7 years. Education staff commented that the use of standing frames is easier with younger children because they can be distracted by play activities, and moving and handling take less time. Parents mentioned that, with younger people, the prevention of hip contractures and the delay of surgery is something that it would be feasible to measure. Clinicians considered age to be unimportant, unless the intervention was to delay the introduction of a standing frame, yet recognised that it would be an impacting variable.

For the physiotherapists the exceptions were if the intervention was 'all year' standing frame use (i.e. including the summer break) versus treatment as usual, in which case a suitable group would be children aged 14 or 15 years, where maintaining function is critical.

Time and again the issue of the variability of how children are affected by CP was raised. Parents commented on the heterogeneity of children with CP and how this could be problematic in a trial as there are 'no two children the same':

*Cerebral palsy affects them in so many different ways. My son's a GMFCS V so he's the most severe but then he doesn't have dystonia, he's got the other type where he gets stiff.*

*Parent group*

The physiotherapy group demonstrated that standing frames were prescribed for different reasons and this was very much dependent on the child:

*What am I using this piece of equipment for? Am I trying to . . . Is it the only way they're going to get any weight bearing? So even if I don't think it's the best way to strengthen their bones it might be the only way available. Or do I want them to be able to stand with their family in the kitchen and cook? Then it's your goals around participation.*

*Physiotherapist group*

Education staff believed that further inclusion criteria would have to be children who (1) could tolerate the standing position, (2) did not have problems with their vision and (3) were able to communicate. Parents concurred and commented that to compare increased standing 'may skew results' if children who could and could not tolerate increased standing were included. Although they did not suggest this in the context of which children to include in a trial, education staff contrasted children who have used a standing frame from a very young age with those, where it has been introduced later, who 'struggle a bit more':

*Kids who have come in from being 3 years old and they've been put in the little standing frames . . . they'll accept it as part of the day because that's what you do, like washing your hands . . . whereas the other kids they haven't got their head around it as much.*

*Education staff group*



### Other challenges

The challenges identified were around the ‘noise’ from other therapies and interventions and the ‘fidelity’ of an intervention. That is, most groups talked about the fact that children would be having other interventions, not solely a standing frame, and how can you determine what results were caused by the standing frame?:

*Because of all the input that children have I think it'd [be] very difficult to define what is exclusively because of the stander.*

Parent group

It was considered unreasonable to stop these other interventions. It was also said that some parents do more at home with their children than others do and it would be difficult to expect them to stop. Parent participants noted that they were not particularly concerned with the lack of research evidence for standing frames. They would always choose the option that may benefit their child, and if they could see a positive outcome, they would continue to do what they think is best:

*I think we do a lot of things for our children where there's very limited evidence, because they are so complex. As parents, we're used to a stab in the dark. If a therapist says 'We think this will help, anecdotally this kind of helps' then we'll try it. It'd be lovely if there was clear evidence, because it would help with funding, getting consistent provision.*

Parent group

Similarly, physiotherapists focused on the needs of the individual young person, and suggested that standing and/or walking was not always the best way to promote positive outcomes for them:

*I think there is an emphasis in paediatric physiotherapy very much on the walking and the standing of the child and it's this goal that we have to achieve walking – even [though] we know now that many children GMFCS IV and V will not achieve independent functional walking, and yet we strive for that in maintaining, in particular, hip extension at the cost of everything else . . . I think we sometimes really need to re-focus . . . We need to look at each child individually and what they're actually doing and how it functions.*

Physiotherapist group

There was some discussion in the clinician group around dependency on the ‘operator’ during a trial and the need to ensure that the child is correctly positioned and secured in the standing frame or whatever is used. Education staff also mentioned a lack of confidence in knowing they had done this correctly with the current standing frames they use in schools. There was the view that the physiotherapists were the most skilled at this. Comments were also made about the design of fastenings when hook and loop fasteners could creep out, or that the child's family might loosen them if they felt they were too tight.

### What did the single stakeholder focus groups add?

The single stakeholder focus groups added greater understanding to the survey 1 results, including highlighting some issues not identified through the survey responses. They provided vital information about potential designs of and the feasibility of a standing frames trial. The main findings are outlined in *Chapter 5*.

Emotional equipoise was an issue across all groups apart from the clinician group. Orthopaedic surgeons and physiotherapists had a strong belief that without standing frames there may be progressive deterioration in young people with CP. The views of parents in particular were entrenched in the idea that standing frames are good, which was not surprising as most had invested time and effort over the years in using them with their children. This would have to be managed in a future trial when recruiting participants.



Parents themselves raised the issue of educating other parents to help them make an informed decision in the context of a trial.

Parents across both the Northern and Southern groups suggested more potential benefits of standing frame use compared with other stakeholders. It was a surprise to parents that there was no robust evidence for standing frame use. Health professionals had a greater awareness of what can/cannot be altered or improved in the condition and mentioned fewer potential benefits of standing frames. A number of the proposed outcomes would require a longitudinal study in order to answer the question about the impact of standing frames. Some would be feasible to measure in some children but not in others, depending on their GMFCS level.

The type of intervention was in some ways determined by the outcome of interest. Physiotherapists stressed that if the goal is to maintain hip integrity the child should be able to move; if the goal is to stretch then the child should not be able to move. The most popular intervention by far, and the one considered to have an impact on participation and probably compliance in standing, was the non-static standing frame, but there would be significant cost implications for this to be a comparator in a trial.

There was no consensus about how long the intervention should last and this would be dependent on the choice of intervention and the outcome of interest.

### **How did the single stakeholder focus groups inform the next step?**

The single stakeholder focus groups provided essential information about potential benefits and challenges of standing frame use. This informed the topic guides for the subsequent interviews and multistakeholder focus groups.



# Chapter 5 Interviews

## Objectives

The objective of the interviews was to explore the attitudes of young people with CP to standing frame use.

## Methods

### Population

Young people were identified as potential participants by their parents, who had completed the survey 1 questionnaire, or through the clinical services of members of the co-applicant group. Young people were eligible to take part if they were aged 8–18 years and currently used or had used a standing frame.

### Topic guide development and conduct of interviews

The young person was given the option to have a communication support person of their choice. At times, the choice of the young person's communication support was crucial to the success of the interview, as it enhanced the young person's understanding of the questions and as well as the interviewer's understanding of their response. A number of steps were taken to ensure the trustworthiness of the interview data. The interviewer (JG) was experienced and confident in communicating with young people. This was enhanced through regular visits to a local specialist school to spend time with young people with CP and learn about their communication methods and equipment use. The interviewer built up a rapport with the young people to enable her to feel confident that they understood the questions and were giving their honest answers, rather than the answers that they felt the researcher would like to hear. Building a rapport took a variety of forms, including playing games, singing, sitting in on classroom activities, chatting about the young person's toys, playing with family pets and generally trying to make the situation informal and fun. Importantly, the interviewer emphasised that she did not know much about standing frames, and as such, it was helpful for the young person to explain both what they liked and disliked about them; they would not get in trouble for anything they said. Furthermore, the interviewer was creative about how they talked to the young people. Answering direct questions was not always possible; alternatives were used such as showing pictures of standing frames, and asking the young person to show the interviewer their own standing frame. Following each interview, the researchers were debriefed to determine whether or not the topic guide should be amended. Only minor changes were deemed necessary to capture aspects of the experience not initially considered; for example, whether or not the young peoples' opinions on standing frames had changed over time and how they would feel if they were not allowed to use a standing frame any more. See *Appendix 6* for the topic guide.

Based on the developmental and cognitive level of the young people we interviewed, discussion about participating in a hypothetical trial was an idea that was too complex and abstract. However, we explored the idea of randomisation by asking the young people about choice in standing (e.g. 'if this group of young people used a standing frame and that group didn't, which group would you rather be in? Should young people be able to choose which group they are in?').

### Procedure

Parents of potential participants were contacted via telephone or e-mail to explain the study. Following this, an information sheet for both parent and young person were sent out. There were two versions of the young people's information sheet to accommodate different methods of communication and cognitive ability. The parents then received a follow-up phone call and if the young person was interested, an interview was arranged. Each young person was offered an opportunity to meet the interviewer for familiarity and topic planning prior to the interview. Recruitment continued until data saturation, defined as three consecutive

interviews not returning new themes,<sup>25</sup> by agreement among the research team. The young people were purposively selected to ensure that there was representation from a range of ages, GMFCS levels, gender, educational settings and regions of the UK.

Assent to participate from the young person and consent from the young person's parent was obtained. The two participants aged 18 years consented for themselves, although this decision was made in collaboration with their parents. All interviews were audio-recorded for transcription and transcribed verbatim. Pseudonyms have been used to preserve anonymity.

## Findings

### Participants

Participants were 12 young people with CP who were currently using or had used standing frames at some point in the past. Their characteristics and experience with standing frames are outlined in *Table 17*. For the participant given the pseudonym Tiffany we have included her mother's quotes as she spoke for her and Tiffany indicated agreement by enthusiastically nodding. Tiffany's mother made comments about Tiffany's experience, then checked whether or not Tiffany agreed. The interviewer then re-confirmed with Tiffany. Although Tiffany had the opportunity to disagree with her mother's statements, it is important to note that she may have felt unable to do this because of her rapport with the interviewer or her relationship with her mother. However, the interviewer was confident that Tiffany could express her opinion comfortably because of conversations unrelated to the interview content; for example, when the interviewer commented that Tiffany must be excited to return to school after holidays, she strongly disagreed.

### Interview format

Interviews were conducted between June and November 2016 at a location of the young person's or carer's choosing. All elected to be interviewed at school or home. These settings were primarily chosen for the participants' comfort and ease of access. At the beginning of the interview, the young people's study information sheet was provided to each participant (and their support people) and the researcher talked them through it, particularly emphasising that they did not have to answer any questions they did not want to, and could stop the interview at any time. Written consent and assent was obtained. Interviews ranged between 10 minutes and 38 seconds and 35 minutes and 11 seconds in length. As a gesture of goodwill, participants were offered a £10 Amazon voucher.

### Attitudes to standing frames

#### Understanding standing frame use

Participants were asked why they used their standing frames. The young people thought that standing frames were primarily used for improving aspects of body structure and body function. In particular, they suggested that standing frames were beneficial for bone strength, leg strength, growth, posture and general physical health:

*[Standing frames help you] to stand up tall and make your legs get straight and not bendy. Make your body stronger, not weaker.*

*Fred*

Another reported physical benefit was an extended stretch of their muscles. Some participants said they really enjoyed this sensation, especially after sitting for long periods. They believed it helped with their overall comfort, particularly in relation to their range of movement (or 'flexibility') and contracture prevention. The standing frame was perceived to be the only way to properly stretch their muscles:

*I'm getting a stretch at every part, your hip flexors, your knees, your hamstrings and because there's no other way . . . where you can get a better stretch.*

*Will*

**TABLE 17** Interview participant characteristics

| Name                 | Sex    | Age (years) | GMFCS | Predominant motor pattern | Age of first standing frame use (years) | Currently using a standing frame? | Standing frame setting | Standing programme                               | Support person in interview   | Communication method in interview   |
|----------------------|--------|-------------|-------|---------------------------|---|-----------------------------------|------------------------|--|-------------------------------|---|
| Connor               | Male   | 8           | IV    | Spasticity                | 2                                       | Yes                               | School                 | More than three times per week for 30–60 minutes | Class teacher                 | Speech, some comments/probing from support person   |
| Olivia               | Female | 9           | IV    | Spasticity                | 1                                       | Yes                               | Home                   | Every day for 30–60 minutes                      | Mother and sister             | Speech, some comments from support people   |
| Kyle                 | Male   | 11          | V     | Dystonia                  | 1                                       | No, stopped aged 9 years          | N/A                    | N/A  | Mother and teaching assistant | Limited speech, comments and probing from support people  |
| Brooke               | Female | 12          | IV    | Mixed                     | 2                                       | Yes                               | Home                   | More than three times per week for 30–60 minutes | Mother                        | Speech, a little input from support person  |
| Will                 | Male   | 13          | IV    | Spasticity                | 6                                       | No, stopped aged 11 years         | N/A                    | N/A  | N/A                           | Speech  |
| Tiffany              | Female | 13          | V     | Dystonia                  | 1                                       | Yes                               | Home                   | More than three times per week for 30–60 minutes | Mother and respite carer      | Voice output communication aid. Comments from support person, Tiffany indicated agreement or disagreement |
| Fred                 | Male   | 14          | IV    | Spasticity                | 3                                       | Yes                               | Home                   | More than three times per week for 30–60 minutes | Mother                        | Limited speech, some comments and probing from support person   |
| Sophia               | Female | 14          | IV    | Spasticity                | 6 or 7                                  | Yes                               | Home                   | Not known  | Friend                        | Speech, a little input from support person  |
| Gemma                | Female | 15          | IV    | Mixed                     | 5                                       | Yes                               | School                 | One per week, < 30 mins                          | N/A                           | Speech  |
| Robert               | Male   | 17          | IV    | Spasticity                | 3                                       | Yes                               | School                 | More than three times per week for 30–60 minutes | Mother                        | Speech, some comments/probing from support person   |
| Maddie               | Female | 18          | IV    | Spasticity                | 6                                       | Yes                               | School                 | More than three times per week for 30–60 minutes | School physiotherapist        | Speech, a little input from support person  |
| Bart                 | Male   | 18          | IV    | Mixed                     | 4                                       | Yes                               | School                 | Once per week for 30–60 minutes                  | N/A                           | Speech  |
| N/A, not applicable. |        |             |       |                           |   |                                   |                        |  |                               |   |

Standing frames gave the participants an opportunity for a change of position, which could be enjoyable for a variety of reasons, including having a 'different view of surroundings', 'being in the upright position' and 'the feeling of being tall'. The importance of a position change was also related to pain management. Although participants enjoyed the mobility and independence of their wheelchairs, sitting for long periods was reported to be 'uncomfortable' and could make the young people 'achy and hurty':

*I know that if I sat in here 24 hours a day, 7 days a week I would get quite tight and I would get probably a lot more pain than I do if I wasn't in the standing frame.*

Bart

Despite these benefits pain was an issue for many of the participants. General pain, knee pain and foot pain were all reported, especially after standing for 'a while' or 'too long':

*I can't, like, wait there for too long because otherwise it hurts my foot.*

Gemma

Pain did not necessarily dissuade the young people from using (or asking to use) their standing frame. Rather, they were pragmatic about their pain and believed it was something to be endured in order to obtain positive outcomes for their physical health. Participants tolerated the discomfort of standing frames and focused instead on the advantages they believed that standing might give them in the long term:

*I had an operation on my hip and they said, 'Not many people get to 17 without needing the hip done.' . . . For me to get to this age with only needing one [hip operated on] is all to do with standing, so there are benefits to go with the pain.*

Bart

Bart also commented that he did not always feel this way. When he was younger, he never wanted to be put in his standing frame. His understanding of the (perceived) importance of standing frame use had developed with age:

*. . . When I was much younger I never wanted to be going in it. I always used to complain . . . Then I would have to go in. Now that I'm older, I feel the benefit of it.*

Bart

### Experience of standing frame use

Being in a standing frame could allow the young people to participate in activities that would otherwise be impossible. Compared with a wheelchair, the standing frame gives the young person a different perspective on the world, and thus they have the freedom to independently engage in different tasks:

*I had a bit more independence as well because I could actually wash the dishes or stand up . . . That is incredible how a stand can change how independent a person is.*

Will

On the other hand, standing frames could also be quite restrictive and inhibited independence. As Olivia commented: 'I cannot get around in the stander like everyone else can. [The powered wheelchair] is 'sort of my legs''. A static standing frame limits the young people's mobility and forces them to rely on others for help:

*There's not many things you can do in the stander that involves you by yourself . . . I do a lot of independent things inside my wheelchair that I can't do in the standing frame.*

Bart

One participant mentioned that using the standing frame was an activity in itself and thus did not facilitate her ability to engage in other tasks. Standing required a lot of effort and concentration, much like going to the gym. Brooke did not see the need to do additional activities while in her standing frame:

*I don't like to do something. I just feel like it's already doing something and I'd rather be in my wheelchair or on the floor when I'm doing anything else.*

Brooke

In addition, standing frame use could be associated with discomfort and pain for a variety of reasons beyond standing for too long (as mentioned previously). Sometimes this was perceived to be caused by the general way the young person's CP presents:

*He tends to pull at everything. That is why in those frames he would extend and pull and twist. That is probably why it ended up being uncomfortable.*

Kyle's mother

Other times, it was related to a specific body part or injury which the standing frame could aggravate. For example, Gemma had particular trouble with her foot, and as such found it difficult to bear weight:

*I don't want to really force myself to use the stander at the moment, because my foot – it doesn't know how it's going to react to it. Because obviously it is getting really, really painful for me to do anything.*

Gemma

Several participants also mentioned how frightening being in a standing frame could be. Because they spent the majority of their life in a wheelchair, standing was an unusual position for them. Sophia commented that standing frames were too high, and she was 'scared of heights'. The fears could persist despite the fact that they knew logically they did not need to be scared while in the standing frame:

*I must seem like a big baby or scaredy-cat to some people, but I am actually genuinely frightened and nervous. No matter how much people say I'm safe, that doesn't help me because I know I'm safe, but a part of my brain just tells me I'm not safe.*

Brooke

Although standing could feel quite strange and scary, some young people suggested that it is possible to become accustomed to the sensation. For young people using a standing frame for the first time they emphasised the importance of self-pacing:

*It is very weird standing at first. But I would say, 'if you're uncomfortable just take your time.' It does take time to get used to one, so I'd say, 'just take your time and build up the confidence.'*

Robert

### **Impact on peer interaction**

Participants often used their standing frames for specific (sometimes solitary) tasks, such as school work. However, their positioning also had an impact on their social interactions, both positively and negatively. Connor found standing frames problematic particularly for peer interaction, describing time in his standing frame as 'boring' and 'stinky'. Using his standing frame at school meant he was much higher/taller than his peers, who sat at desks. This meant it was difficult to engage socially:

**Connor's teacher:** *I think that you like your chair better than your stander because . . . when you're in your stander you're a bit higher than everyone else . . . You don't like standing up, separate.*

**Connor:** *It's really boring, isn't it?*

However, another participant felt that being in a standing frame improved her peer interaction, particularly when she had attended a mainstream school. Standing allowed her to 'fit in':

*The able-bodied children would relate to her differently and she was more like them because she was upright. It's strange just changing position meant that.*

*Tiffany's mother*

### **Play**

Olivia used her standing frame routinely for many tasks, such as toileting, eating and drinking. However, it also featured regularly in her play, especially with her sister, Olga:

*I do painting and colouring and marking, like playing schools.*

*Olivia*

Olivia stood in her frame to give herself a more dominant role in games, such as pretending to be a school teacher in front of her 'class'. Her sister sometimes 'wants to be disabled' during play, so puts herself into the standing frame. Their mother noted that play between the sisters naturally incorporated the standing frame which, as a by-product, then teaches Olga about Olivia's care needs. For example, as part of their role-playing games, Olga would strap Olivia in her hoist or position her in the standing frame.

### **Choice in standing**

The young person's choice about if and when they use their standing frame was a particularly salient issue. One young person was very keen to use a standing frame but did not have access to one. Others were frustrated about having to stand even though they did not want to. Some young people were happy not to have a choice about their standing:

*I don't mind what they say. I just go in the stander.*

*Fred*

Although some participants technically had a choice about when they used their standing frame (e.g. they were asked whether or not they want to stand rather than being told they have to), they experienced negative reactions when they chose not to stand:

*It is just the fact that we have to stand it for quite a long time . . . I can say no, but I always get moaned at for saying no because it is what is best for me.*

*Sophia*

Many young people preferred the comfort and independence of their wheelchair over being stationary in a standing frame. Several participants commented on how society has dictated 'normal' postural positioning, which did not suit them as individuals:

*I'm not a big fan of standing and I call it 'the fault of life' because I'm like, 'Why do we have to?' It's like, 'Why was this even invented and why did the world turn out this way?'.*

*Brooke*

Interestingly, when asked if young people should have a choice about using a standing frame, one participant suggested that they should not:

*Even though it's pretty horrible to say, it's probably the best thing for them, because when I was much younger I never wanted to be going in it . . . [but] now that I'm older, I feel the benefit of it.*

*Bart*



Bart emphasised the need to explain the potential benefits of using a standing frame, even to very young children. This type of pragmatism was again evident when young people thought about long-term goals, rather than the discomfort of standing. They could weigh up the positive and negative aspects and make their choice about whether or not to stand:

*I ask to go in it because I know it will help me with standing, but I'm reluctant to actually. I don't really feel like the whole of me wants to go.*

Brooke

Although the young people discussed many obstacles, one factor that actually helped them to use their standing frame was emotional support. It was important to have an opportunity to complain every so often, even if the young person was generally willing to use their standing frame:

*My mum is very good. She listens to me. Even though she might be tired about it and heard it five million times, she still goes, 'OK,' and still tries to talk me through it because she's my mum and she's very supportive. All my family are really supportive.*

Brooke

### Challenges of standing frames

A major challenge for standing frame use was the manual lifting and handling it requires. Generally, two people were needed to make it possible for the young person to be positioned properly in their standing frame:

*It's a right job to get you transferred from the chair into the standing frame, and then out the standing frame into the chair.*

Robert

The person or people positioning the young person not having the requisite skills could also be problematic, affecting the young person's ability to use their standing frame. The carers required comprehensive training to ensure that the young person is comfortable and has their needs met:

*It hurts because some people ping it so hard and I feel like saying, 'Do you want to hurt me? Do you want to . . .?' But I don't . . .*

Olivia

This issue was exacerbated for Tiffany, who had to have her VOCA adjusted with the change of position. If it was not set up correctly, she could not communicate the way she needed to while standing:

*I think the challenge is with the people helping her need to know the equipment well and need to know how to position the communication equipment for her.*

Tiffany's mother

Another challenge when using the standing frame was interference from siblings. Parts of the standing frame (e.g. the angle adjustments) were at an accessible height for siblings, which could leave the young person in the standing frame vulnerable:

*You used to happily be standing in it and then [your brother] used to adjust it and you used to be at a funny angle. Or he would take all your toys away.*

Kyle's mother

### Standing frame design

The young people were particularly concerned with the type of standing frame they were using. It was important for them to feel safe and comfortable. As it was also desirable to be able to distract themselves

from the pain, the young people tried to engage themselves in activities to keep themselves occupied. Some types of standing frame enhanced their ability to do this because of the size or attachments. For example, standing frames with tray attachments enabled them to enjoy particular activities independently:

*The older ones have a tray or bowl in the middle so you could put cake mixture in it. There was a plastic tray that goes on top of the bowl . . . it's the world's best invention.*

Will

Participants suggested that having a TV or music player connected to the frame would be beneficial. Aesthetics were thought to be important too and it was felt that young people would be more enthusiastic about using their standing frames if they could choose the colours and patterns. It would make standing less 'boring':

*[I'd] change the colour of the standing frame because it's boring . . . It would look colourful and look nice.*

Maddie

Flexibility of the standing frame was also valued. Tiffany's sit-to-stand frame was favoured because the level of stretch she received could be adjusted depending on her tolerance each day. An added benefit of this type of standing frame was that Tiffany had the independence to control her own standing (and comfort) using the levers:

*She can say when it's a comfortable stretch. Different days can be different, so she could have a bigger stretch one day and a smaller stretch another day . . . when she's had enough she can let herself back down for the sitting position.*

Tiffany's mother

### Size: lack of space

Another challenge of standing frames is their physical size. Standing frames take up a lot of space, and this causes difficulty in the home. It also means that the standing frame cannot always be used as intended. For example, Kyle was not able to move around in his dynamic stander:

*The stand was at the back and the back legs came out so far that we couldn't actually move me in it that well.*

Kyle

Some young people overcame this issue by storing and using their standing frame at a place that is big enough, for example, school:

*I tend to use it at school because we really haven't got the space at home to accommodate it, have we?*

Robert

## What did the interviews add?

The interviews provided essential information regarding young people's perceptions and experiences of using standing frames. Based on PPI advice and the experience of the co-applicant team, this was the most appropriate way to gain young people's views (as opposed to the surveys and focus groups that were used for other stakeholders). Therefore, these interviews were a proxy for the stages of the Understanding Frames study that were inaccessible for young people with CP. The interviews have shown that young people have clear opinions but do not often get the chance to express them. Feelings about standing frames are unique to the individual; however, we now know that participation and activity engagement are particularly important to young people.

## How did the interviews inform the next step?

The interviews informed the co-applicant team's understanding of how a research trial might feasibly be designed, keeping in mind the issues that are most important to the users themselves (e.g. participation). This was particularly useful in the final stages of the study, when different trial designs were being considered.



# Chapter 6 Multistakeholder focus groups

## Objectives

The objective of the multistakeholder focus groups was to explore views on the acceptability and feasibility of potential trial designs to examine the clinical effectiveness of standing frame use in young people with CP. Mixed groups were chosen to allow for rich and meaningful discussions between different stakeholders.

## Methods

### Population

Eligibility was the same as for the single stakeholder focus groups, for parents and professionals. None of the single stakeholder focus group participants were approached as we did not want the group to be influenced by previous discussions. Again, potential participants were sought from survey 1 who were willing to take part in further stages of the research (with priority given to those approached for the single stakeholder focus groups who had expressed keen interest but were unable to attend) and personal contacts.

A shortlist of potential participants was created by Jill Cadwgan, Sarah Crombie, Jan Lecouturier and Jane Goodwin to ensure a sample with representation from a variety of stakeholders, including, but not limited to, physiotherapists, parents, paediatricians, orthopaedic surgeons and education professionals.

### Topic guide development and conduct of focus groups

A topic guide was developed based on the previous stages to examine the stakeholders' perceptions of standing frames research. Topics included (1) perceptions of research priorities, (2) acceptable periods of non-use and (3) support needs to ensure that a standing frame is used as prescribed. A brief PowerPoint presentation of the study results thus far was made at the start of the focus groups to inform the participants and frame the discussion of pertinent issues. See *Appendix 7* for the PowerPoint presentation and topic guide.

### Procedure

Two multistakeholder focus groups were conducted. One focus group was held in the north and the other was held in the south of England to allow for a representative sample without requiring too much travel for participants. Multistakeholder focus groups were convened to allow for discussion between different stakeholder groups.

The process of contacting and recruiting participants was identical for each of the focus groups. Potential participants were contacted via telephone or e-mail to explain the study, then an information sheet was e-mailed or posted to them if they expressed an interest. Written consent was obtained on the day of the focus groups before discussion commenced. Focus groups were digitally recorded with the permission of the participants. Sound files were transcribed verbatim and anonymised.

## Findings

### Participants

Two focus groups were convened in December 2016, one in the north and one in the south of England. In the Northern group, participants were two education professionals (mainstream – classroom support assistants), one parent, one orthopaedic surgeon, one neurodisability paediatrician, one paediatric neurologist, one research occupational therapist and one physiotherapist. In the Southern group, participants were

five physiotherapists, one community occupational therapist, one paediatrician and one education professional (early years key worker). Although we invited three–five parents to each of these focus groups and had confirmed attendance, many cancelled at the last minute because of their child's health. Therefore, we only had one parent participant across both groups.

### **Focus group format**

Focus groups were scheduled for 2 hours and refreshments were provided. Participants were offered a £10 Amazon voucher as a gesture of goodwill. At the beginning, the study information sheet was provided to each participant and they were given time to read it through. Written consent was obtained and the ground rules were agreed. Before the discussion, and to set the scene, a member of the research team gave a 10 minute presentation. This presentation covered results to date from survey 1, the single stakeholder focus groups and interviews, potential PICOTS for a standing frames trial, the purpose of the focus groups and the topic questions.

The findings are outlined here in the PICOTS framework, to provide a clear outline of how the data from these multistakeholder focus groups could be incorporated into a standing frames trial. A section about the participants' reservations for a trial has also been added to highlight the potential challenges, particularly regarding ethics issues of research in this population.

### **Population**

Throughout the focus group discussions and the exploration of the most appropriate group to participate in a future trial, it was clear that the age, GMFCS level and cognitive ability would determine the choice of intervention and/or the outcome. Participants also noted that age, school setting and cognitive ability may have an impact on standing frame perceptions.

#### **Age**

It was thought that an intervention to introduce standing frame use in the 6-week summer break would be problematic in the preschool-age young people who tend to have a standing frame in the home. This would require those randomised to the control group to stop using their standing frame at home, which was considered 'tricky' and unlikely to be acceptable to parents. However, older young people usually do not have a standing frame at home because of the lack of space and could be a suitable group for such a design. In addition, it was recognised that preschool children generally enjoy being in their standing frames; it is the older children who often are reluctant and this could have implications for compliance in a future study. Nevertheless, participants in the South felt that a range of ages should be included and divided into preschool, primary and secondary school children, but the issue of conducting a trial in mainstream schools was acknowledged as something that would have to be thought through. Issues highlighted in the single stakeholder groups about the potential for children or young people in mainstream schools to feel isolated if they are the only people standing in the classroom were also raised.

#### **Gross Motor Function Classification System level**

Gross Motor Function Classification System level was an important consideration for all focus group participants. The groups reported that some young people were put in standing frames unnecessarily, for example, with GMFCS II, because the activities they could do, such as walking, were likely to have more impact on bone density and hip migration than passive standing. This means that GMFCS I and II would be considered groups to exclude from a standing frame study. Owing to the variation in how children are affected by CP across and within the GMFCS levels, selection of the most appropriate level for any research study was felt to be crucial. Alternatively, if a range of levels was included then they could potentially be separated at the analysis stage:

*I think even within one level you can get so much variation that you're going to find it really difficult to show significant differences unless that group is really, really narrow.*

*Southern group – physiotherapist*

The intervention of the use of standing frames in the summer break was also thought to be more appropriate for GMFCS IV and V. This group of children ‘would be the ones who would probably deteriorate’ if they were not using a standing frame and a difference could be detected in those who continue standing throughout the break. Participants commented that the selection of GMFCS level would also determine the type of equipment used in a trial:

*So like for the GMFCS level IV and maybe some of the Vs you could look at, for example, a kid walker versus a standing frame.*

*Southern group – physiotherapist*

If the outcome of interest is participation, this could look very different, as the activities would vary considerably depending on GMFCS level. If hip dislocation is the selected outcome then participants were not convinced that the standing frame would help young people with more severe CP, such as GMFCS V:

*I think a lot of parents have a lot of guilt and . . . the last thing we want to do as therapists is add to that guilt. So if they think, ‘if my child isn’t in their standing frame twice a day for 30 minutes then now they’ve got contractures or their hip is dislocated, this is all my fault.’ Well, the evidence quite strongly shows us that’s not the case and that that was going to happen regardless of whether they were in the standing frame or not.*

*Southern group – physiotherapist*

## Cognitive ability

The fact that some children do not enjoy being in a standing frame, and find standing painful, was raised. One suggestion for future research was to explore whether or not the standing frame is useful for the individual and whether or not they choose to use it. In the Southern group, cognitive ability was raised as a potential barrier to measuring participation if it were chosen as an outcome, particularly if the means of measurement was feedback from the child or young person or an interview. This was picked up in the Northern group, where there was some frustration about young people with severe learning disabilities generally being excluded from research; differences in intellectual functioning may be related to standing frame experiences, and a research trial must capture this:

*I do struggle sometimes, because there’s so much research for children who can show an ability, or do motor skills, or this, that and the other. It’s like, ‘oh, OK. Could you just try and find a way to help those who can’t? Who haven’t got the motor skills, who can’t do a clear yes/no?’ But I absolutely appreciate that it’s incredibly difficult to find a way to do it.*

*Northern group – parent*

Both groups were particularly keen to make the study as inclusive as possible and a possible solution was proposed that parents could act as a proxy to read the young person’s ‘signs’. For example, a smile can mean they enjoy standing.

## Intervention

The interventions discussed in the focus groups were: no standing versus standing, increased standing time and comparison of different types of standing frames.

## No standing versus standing

With a treatment versus no treatment trial, participants noted the difficulty of measuring outcomes such as body structure and body function outcomes because treatment would need to be withdrawn for too long to see any difference:

*You’d have to remove it for long enough to actually believe there could be a difference. If you were going to be thinking about ‘does using the standing frame help constipation?’ ‘Does using the standing frame make a child less stiff or reduce their tone?’ . . . You’d have to remove it for quite a long period.*

*Southern group – physiotherapist*

Withdrawing standing frames when they are already used in routine practice was considered problematic (and potentially unethical), and other 24-hour postural management may have an effect on a study's outcome measures. It was thought that families would be uncomfortable with withdrawing standing frames as an intervention, as some believe 'that it's really making a difference to their child'. Even if parents did accept withdrawal, what would parents consider an acceptable period? What they think is acceptable may not be sufficient time to measure any changes.

### Increased standing time versus current standing time

Based on the experience of a number of participants in the Southern group who have cared for young people with CP who disliked standing, there was a slightly more negative view of standing frames. They felt compliance with increased standing could be a major problem. There were certain young people for whom standing improved things like function, integration and communication, and compliance would not be a problem; it would be possible to select such young people, but this would have implications for trial design. On the other hand, in the Northern group standing duration was considered to be a viable option, but the most appropriate outcome would be difficult to determine, practical issues were identified and it may not be feasible in practice:

*In terms of looking at an outcome like bone density – frames are already widely used, you're not looking at a study that would be no use of the standing frame over 6 years. So it's going to be a difference in time. So we have to say, 'how much more would they have to do to be different from what is used now, and closer to where they need to be?' It's then very difficult to power the difference, and it may not be practical. Although it may be something that we all want to know the answer to . . . it's just too difficult to detect the difference, because we can't go back to zero, we can't go back in time and not use standing frames.*

*Northern group – orthopaedic surgeon*

The practicalities of implementing an increased standing time intervention in schools were also raised.

Another option, rather than increased time standing per day, would be to continue standing for a group of young people over the 6-week summer break. A number of participants in the Northern group expressed views on the impact of the 6-week break in standing:

*A lot of physios will tell you that children who haven't stood over the 6-week holiday do come back to school more contracted, less head control . . . it may be that you could look at that side of things for some children.*

*Northern group – physiotherapist*

However, one person in the group asked whether or not this deterioration over the holiday period was 'retrievable':

*Hey, we can get back there, and actually they've had some mental space during their holiday.*

*Northern group – paediatric neurologist*

It was generally agreed that this intervention would be more suitable with older children who are unlikely to have and use a standing frame in the home. Then there would be no need to ask certain families to stop using the standing frame if they were randomised into the control group. The logistics were discussed, in particular where young people would go to use a standing frame in the summer break; several suggestions were made, including specialist schools' facilities, although this could result in a long distance to travel for some families.

### Delayed standing

Delaying the introduction of a standing frame at the time when the young person was diagnosed with CP was discussed in the groups. Some participants thought that delaying standing frame use would be



acceptable from a clinical perspective but not to parents. The parent perspective was that the point when parents receive the diagnosis is too stressful a time to make such a decision:

*At an early stage you're just bombarded. You're in this new world and you just don't know what to do, where to turn and to be faced with a decision like 'Are you happy for your child to be delayed starting?' It's a massive, massive decision to take.*

*Northern group – parent*

This led to a discussion about equipoise and that 'many therapists and many clinicians will perceive (standing frames) as best practice'. Furthermore, standing frames are already used and being prescribed. Both of these factors make it difficult for parents to believe that they may not be of benefit.

In the Southern group, delayed standing was not discussed in any depth. However, during the discussion of the results of survey 1, one participant expressed reservations about the early introduction of standing frames:

*The ages that we are recommending, so we are going down sometimes even young than a year to start standing up and I'm not always sure parents are ready for that equipment to be in their lives because they have not really had time to come to terms with their child's diagnosis.*

*Southern group – physiotherapist*

Similarly, in the Southern group a discussion about equipoise ensued. This was in relation to therapists and the need for honesty when explaining to parents the reasons a standing frame is being prescribed and the lack of evidence for their use.

### Comparison of different standing frames

There was also discussion about the type of standing frame a research trial could and should use. Rather than withdraw standing, one preference was to introduce something different. The Southern group thought that it would be worthwhile comparing static standing versus a supportive walker (or equipment such as trikes). The intervention might be more enjoyable if it was more active, because the young person and their family might be more motivated to use it. There might need to be different comparators for each GMFCS level, and it would be challenging to do such a study:

*It means it would be easier to do a comparison, I think, with supported walkers instead. It depends. I still think that the outcome should be about child activity and participation. It's not going to be easy.*

*Southern group – physiotherapist*

Participants in the Northern group concluded that the type of frame probably does not matter as long as the young person is as perpendicular as possible:

*I do not know whether it makes such a huge difference once the child's standing. If they are in the most appropriate frame for them, then I would not think that would make a huge difference.*

*Northern group – physiotherapist*

However, participants in the Southern group noted challenges with this approach; different needs were met for young people with CP in terms of standing frame type, positioning and alignment. This was seen as creating difficulties for standardising standing frame practice for the purposes of a research trial, and impacting on outcome variables related to activity and participation:

*There does not seem to be consensus as to the best, the right way – not only the best standing frame, but the best way of positioning and placing a child and that may, again, impact on the activity and participation that's possible, the comfort that's possible, you know, how are they going to deal with that, that there is some children who are more difficult to position than others? What's your best possible alignment? What do we mean by that?*

*Southern group – physiotherapist*

Participants in the Southern group suggested choosing a specific standing frame for a trial because 'otherwise you're not comparing like with like'.

Although driven primarily by the outcome of participation, a comparison of standing versus sitting was suggested. This would involve the young person carrying out an activity they enjoy (tailored for each person) in their standing frame and in their wheelchair. It may require qualitative methods, observing whether or not the young person seems happier if they are not able to express this themselves, and quantitative, for example, measuring whether or not they can engage in the activity for longer. Outcomes could be determined for each individual, rather than having an overall outcome measure across participants. That is, using an individualised, goal-oriented outcome.

### Comparator

A number of the controls or comparators have been described in relation to the intervention: standing frame as currently prescribed (treatment as usual). The Southern group also suggested identifying a place where standing frames are not prescribed to compare with groups who do use standing frames. Certain variables related to activity and participation may be compared in this way:

*I think it's a really interesting idea is finding a natural group where people do not stand, so using countries where people perhaps cannot access . . . You could measure the same, from a participation point of view.*

*Southern group – physiotherapist*

However, the other participants pointed out that the trial would then need to consider confounders such as culture, diet and medication differences.

### Outcome

Participants believed that it is important to have information about the body structure and functional benefits of standing frames as primary evidence for their use. The parent participant commented that the standing frame helped with digestion and bowel movements, and if these are not managed correctly, there is an effect on the rest of the young person's functioning (and the family's happiness). The young person's quality of life is also extremely important. Although these are potential outcome variables, it is difficult for parents to isolate each benefit of standing frame use, as they all overlap:

*If I picked one, I cannot single them, but two. The first one that has an impact on lots of other things [is] his digestion and bowel movement. If he gets constipated, that has a real knock-on effect on everything he can do. So helping his bowel and digestion actually facilitates him doing lots of other things. Then the second one is just his enjoyment. He just absolutely loves standing up.*

*Northern group – parent*

What came across quite strongly in the groups was the importance participants placed on measuring activity and participation in activities as outcomes of standing frame use. When considering the benefits of standing frames, the views of equipment users are most important. Participants believed that what is measured should be guided by what young people want. It was suggested that we need to investigate whether or not standing is a positive experience for the young person, and if so, in what way. The young person's motivation for standing must be considered, especially if they did an activity they particularly liked or disliked in a standing frame:

*I think we need to focus on the users of that equipment . . . regardless of what it provides for everyone else. Because an added benefit . . . would be improved alignment or reduced bone density or reduced joint contractures. But their actual ability to participate with their friends does much more for their confidence and their self-esteem.*

*Southern group – physiotherapist*

*Professionals monitor . . . the body structure and function, and then there is more what I call a subjective benefit, related to the participation and the activity, and then there's the question of the environment. I call that subjective, because I believe what the family feeds back to me, or the physio feeds back to me.*

*Northern group – orthopaedic surgeon*

Throughout the discussion, participants commented that outcome variables for a trial would also depend on the young person's age, GMFCS level and school setting. They felt that it would be difficult to design a trial because therapies were tailored to the individual, and there would be challenges investigating each potential benefit. Each benefit might require a different approach to investigation and different resource depending on the intervention and outcome. For example, the 'change of position' identified by parents as important was considered likely to be part of pain management. Other comparator positions might be painful (e.g. lying on their stomach), so this would need to be considered when designing a trial:

*Yes, but they do not like that [lying on their stomach], and also most young children, especially the ones that have got poor head control, hate going on their tummy.*

*Northern group – physiotherapist*

Participants suggested that a mixed-methods approach would be appropriate to explore the clinical effectiveness of standing frames because, although functional assessments are important, qualitative research can provide rich insights on life:

*You can do both quantitative and qualitative. So you can use your health-related quality-of-life measures. You can use your CP child, you can use elements of functional assessment, functional outcome. But I think it would be a strongly important thing to have a reflection running alongside . . .*

*Southern group – paediatrician*

## Timing

Owing to the in-depth discussion and focus on the most appropriate intervention and outcome, the duration of a potential trial and data collection time points were not discussed in great depth. Where this was discussed was in relation to withdrawal of standing frame. Apart from the fact this may not be popular with parents, one participant commented that a 6-week to 3-month withdrawal period would be required for a difference in body structure to become noticeable. Another person felt that up to 3 months' withdrawal was too short and indicative of the problem with previous research:

*All the bad evidence that is out there is because it's done for too short a period of time with too little follow-up. Imagine if you, fundamentally, really want to look at something, it's got to be a long trial and it's got to have a long-term follow-up. A lot of decisions are being made . . . on poor quality data short period and it's not appropriate.*

*Southern group – paediatrician*

In the Southern group, the importance of study duration and follow-up was emphasised. It was expressed that 2 years might not be long enough to determine the impact of using/not using a standing frame. In terms of securing a research grant, it was thought that funding for a 2-year intervention study was feasible but ideally, there should be scope to follow participants up over a further 2 years. This led the group to suggest a cohort study rather than a trial:

*This is not some sort of thing that you can get a big difference quickly by doing something. This is almost a cohort trial rather than anything that is more specifically interventional. So you are probably going to be having to look at relatively high numbers.*

*Southern group – paediatrician*

*Also, if it was a cohort you could follow the same children through that age range as well instead of having different children, which would be a helpful thing to do.*

*Southern group – physiotherapist*

### Setting

Participants perceived that few young people use standing frames in mainstream schools, especially secondary school, as a result of logistics, such as changing classrooms, stairs and young people wanting to sit like their peers. Therefore, a standing frames trial should focus on young people at specialist schools.

The intervention to extend standing frame use in the summer break could be challenging because there may not be enough caregivers or physical space for the young person to use their standing frame. Furthermore, a lot of other things change during this period (e.g. therapy), and it would be difficult to determine what impact was caused by the standing frame:

*We see a lot of the children who come up for surgery, who have interventions. They always want to come in the holidays to kind of deal with it, that's another confounding – how do you exclude people from the study. So do you exclude people who are having botulinum toxin injections or surgery . . .*

*Southern group – physiotherapist*

### Reservations about a trial

Participants acknowledged that a trial would be difficult because of the variation in CP presentation and the individual benefits the standing frame has. Furthermore, some benefits are unlikely to be anticipated during prescription, such as 'feeling tall'. The young person's well-being is important, and careful consideration must be given to the priorities in their life at the time. Standing frames should not be used at the cost of all other activities:

*When there is a split placement, it's more important that they are doing the things that they are coming to a mainstream school for. Well, I think it is, than actually being in a standing frame at that time. There are other opportunities to be in a standing frame.*

*Northern group – physiotherapist*

There were a number of issues highlighted that should be explored. First, withdrawing treatment may not be acceptable to parents, young people or health professionals. It is important to know what it means for the young person to not be able to access their standing frame. Furthermore, if not standing results in loss of function, can it be regained?

Secondly, parents may question delaying standing frame use when it is considered best (or at least routine) practice. Along with this, when considering a trial with younger children (e.g. delayed start), participants emphasised that it would be essential to be mindful of the parents' journey with CP. Parents are bombarded with information at the time of diagnosis and rely on people to help them navigate. They may not be able to consent and fully understand the implications of participation. Seeing their child standing can be very emotional for parents. It remains a salient memory even years later. Therapists in the Southern group spoke of their responsibility to be honest in the way they introduce standing frames. They wanted to work towards honest goals with families to avoid adding guilt and burden. Open communication is required so families understand that therapies can be adapted and adjusted. Potential benefit needs to be balanced with what is possible and comfortable:

*I think that's one of the challenges isn't it, working long term, is to be open and honest and to say, 'we are working together on this. And if it's not working for you or your child, you must tell us, so that we can adapt it or adjust it.' As you said, be honest and say, 'these are the reasons we are using it.'*

*Southern group – physiotherapist*

Similarly, despite the perceived need for evidence, focus group participants from the South particularly warned of creating unnecessary emotional distress for families through a trial. Tension may arise between parents and young people if the young person was forced to use the standing frame even if it was uncomfortable. Parents can also feel guilty for not using the standing frame if they believed that they were effective:

*They also have that guilt of not knowing [who] to listen to when their children is complaining in pain. And they still feel obliged to put their child in a standing frame, because they believe all of these things will go wrong, if they do not. And I think we do not help parent and child relationships in that instance, because we have got a child who's saying they do not want to do it and we are causing a level of conflict between the parent and the child, which in any other situation, where the child did not have a disability we would not necessarily accept. So I think we open ourselves up to affecting that sort of family relationship.*

*Southern group – physiotherapist*

Finally, in order to take part in a standing frame trial, the people positioning the young person would need to have adequate training to achieve the optimum effect. This could be feasible using technology:

*You could make little videos on iPads [Apple Inc. Cupertino, CA, USA] that the school have.*

*Northern group – occupational therapist*

## What did the multistakeholder focus groups add?

The multistakeholder focus groups added more in-depth clinical insight into potential trial designs for different stakeholder groups and reinforced some of the findings from the single stakeholder groups. The variety of participants allowed for rich discussion of the different priorities for each stakeholder group. Participants delineated appropriate parameters for each section of the PICOTS. There would be interaction between each aspect; for example, the chosen outcome would affect the type of participants (in terms of age, GMFCS level and cognitive ability) and vice versa. A mixed-methods design was repeatedly suggested in order to adequately capture the outcomes and experiences of young people with CP.

Generally, both focus groups from the North and South were in agreement, with a few exceptions. The Northern group believed that the type of standing frame used would not affect the study (as long as it was prescribed appropriately for the individual), whereas the Southern group felt that the type of standing frame would need to be the same to properly compare the young people. However, this would reduce the potential participant pool, as only some young people would be suitable for a specified standing frame.

For a trial, there would be barriers to overcome for all stakeholders as each person brings their unique experiences and biases to their perceptions of the value of standing frames. Professionals, parents, and young people are not in emotional equipoise despite understanding the evidential equipoise. Standing frames are currently regularly used as part of postural management, and some participants believed that this indicates they are clinically effective.

## How did the multistakeholder focus groups inform the next step?

Overall, there was a strong theme throughout the multistakeholder focus groups of participation and/or the young person's well-being. All stakeholders emphasised how important it is to consider the individual, because young people with CP are different in many ways. This is a major challenge to a standing frames trial. Studies related to long-term body structure outcomes are unlikely to be feasible or funded. This is because of difficulties with timelines (e.g. length of time required to show differences in body structure), populations (e.g. variation in young people with CP), and confounders (e.g. other therapies). Therefore,

innovative thinking is required to design a research study that is feasible. It is important to give insight into the clinical benefit of standing frames beyond body structure and body function, including participation and quality of life. A mixed-methods design, with a qualitative process evaluation, alongside a RCT and economic evaluation, is likely to be most appropriate to capture the broader experiences of the young people, their families and professionals (health care and education), as well as the clinical effectiveness and cost-effectiveness end points. The information provided by the multistakeholder focus groups informed the questions for survey 2, which explored the acceptability and feasibility of a research trial.

## Chapter 7 Survey 2: research trial acceptability and feasibility

### Objectives

A survey was conducted from April to May 2017 to explore the perceived value of standing frames research. Opinions were gathered on a specific research design as well as the practicalities of conducting the research more generally, including feasibility and acceptability. Owing to the anonymous nature of the questionnaires, it was impossible to determine how many participants took part in both survey 1 and survey 2 or to link responses across the two surveys.

### Methods

#### Population

Three populations in the UK were sampled for this study:

- Health professionals: physiotherapists and paediatricians who work or have worked with young people with CP who use standing frames.
- Education professionals: teachers who work or have worked with young people with CP who use standing frames.
- Parents: parents of young people with CP who currently use or have used a standing frame.

Young people with CP who currently use or have used a standing frame were not participants in this stage of the study because completing a survey was not an appropriate way to collect their data. This is because young people with CP GMFCS III–V have a variety of communication methods, and reading and writing are less likely to be an accessible communication style for this particular group. However, we included young people's voices in the interview stage, and used parents as a proxies (surveys, focus groups and PPI).

#### Questionnaire development: research trial acceptability and feasibility

Survey 2 was developed using the same procedure as survey 1. The questionnaire was devised based on the information gathered in the previous stages of the study. Separate versions of the questionnaire were designed for the three participant populations to ensure that the questions were relevant and used appropriate language, although all versions explored similar concepts.

The questions related to the perceived value of standing frames research and opinions about how a research study could be conducted (e.g. Which age group of young people with CP do you think would be most suitable for a standing frames research study?). Furthermore, an example research study was presented, and participants were asked to provide their views about its feasibility and factors that would prevent them from recruiting to, or participating in, such a study. Most questions had fixed-choice responses with a free-text box to explain the response (see *Appendices 8–10*).

#### Procedure

Survey 2 followed the same procedure as survey 1 (see *Chapter 3*) and was conducted from April to May 2017. As per protocol, ethics approval was sought and approved for the final version of survey 2, as it was dependent on the results from all previous stages of the study.



## Results

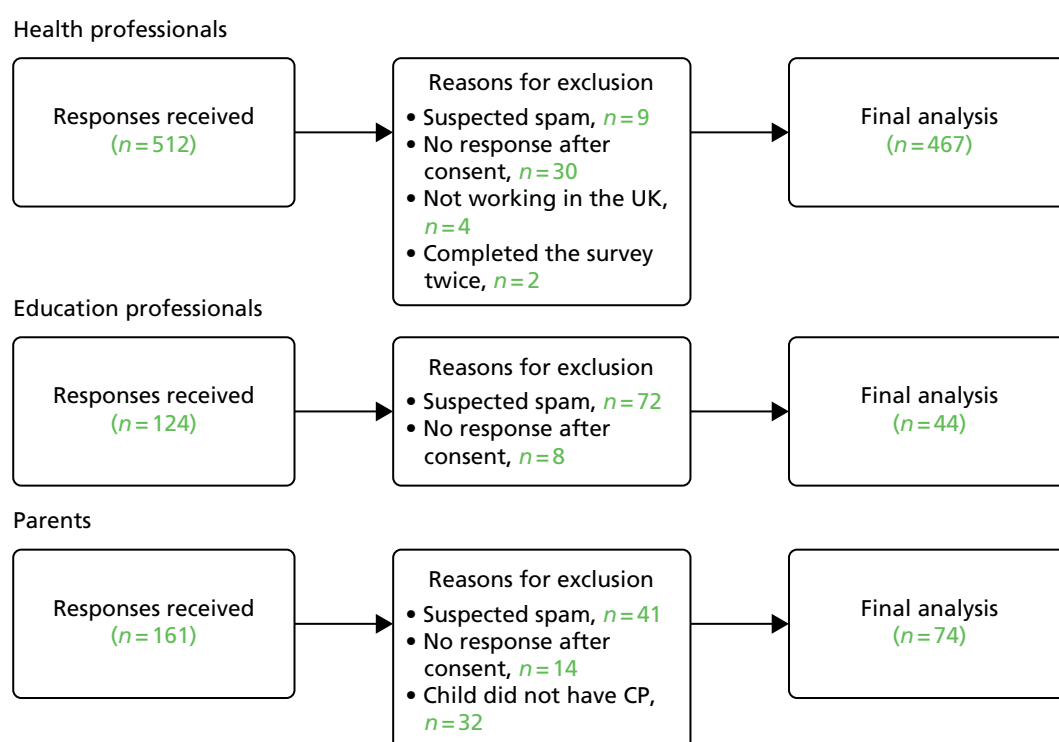
### Participants

Numbers included in the final analysis are presented here. *Figure 3* indicates participant flow through the study from responses received to responses included in the final analysis. In survey 2, we did not distinguish between prescribers and non-prescribers as per survey 1 (current UK standing frame practice; see *Chapter 3*):

- Health professionals – physiotherapists and paediatricians who work with young people with CP who use standing frames,  $n = 467$ .
- Education professionals – teachers who work with young people with CP who use standing frames,  $n = 44$ .
- Parents – parents of young people with CP who currently use or have used a standing frame,  $n = 74$ .

Unfortunately, during recruitment, we identified that there was a sudden significant increase in responses over a 12-hour period. The responses did not seem genuine; for example, false postcodes and unusual e-mail addresses were provided, there were odd responding patterns (e.g. participants identifying as physiotherapists and parents and paediatricians and speech pathologists), and answers were in Chinese script. Following urgent co-applicant discussion, the surveys were closed. On the next working day, Jill Cadwgan sought advice from the HTA and the chair of the steering committee. It was decided that further recruitment should be discontinued for the following reasons:

1. Genuine responses were reviewed. Participants provided the first two letters of their postcode, and we could see that there was already a spread across the UK.
2. A detailed examination of the responses, including the open-ended answers, revealed a consistent message. It seemed unlikely that new participants would add new information.
3. We analysed the data using descriptive statistics only. Therefore, we did not need a certain amount of participant numbers to meet the assumptions of any statistical tests.
4. It would have required a significant amount of resources, may have delayed study progress and may have only resulted in an extra few responses.
5. We felt that our resources in the closing months of the study would be better spent engaging with key stakeholders to inform our recommendations.



**FIGURE 3** Survey 2: participant flow through the study from responses received to responses included in the final analysis.



Table 18 outlines the respondent characteristics. Most health-care respondents were physiotherapists (83.5%) and most education respondents were classroom teachers or support assistants (77.3%). The majority of health professionals worked in community settings: at home ( $n = 300$ ), in specialist education ( $n = 299$ ), and/or in mainstream education ( $n = 272$ ) (multiple responses were allowed). Education professionals tended to work in specialist schools (79.9%). Seventy-four per cent of parent respondents had a child who currently used a standing frame and most had a child who attended a specialist school (64.8%).

**TABLE 18** Characteristics of the two professional groups, and the children whose parents responded

| Characteristic   | Health professionals,<br><i>n</i> (%) | Education professionals,<br><i>n</i> (%) | Parents,<br><i>n</i> (%) |
|--|---------------------------------------|--|--------------------------|
| Role <sup>a</sup>                                      |                                       |  |                          |
| Physiotherapist  | 390 (83.5)                            | –  | –                        |
| Paediatrician  | 24 (5.1)                              | –  | –                        |
| Therapy assistant or technical instructor              | 21 (4.5)                              | –  | –                        |
| Occupational therapist                                 | 15 (3.2)                              | –  | –                        |
| Other  | 10 (2.1)                              | 4 (9.2)                                  | –                        |
| Orthopaedic surgeon                                    | 4 (0.9)                               | –  | –                        |
| Classroom teacher or support teacher                   | 2 (0.4)                               | 34 (77.3)                                | –                        |
| Parent   | 1 (0.2)                               | –  | 74 (100)                 |
| Health professional                                    | –                                     | 7 (15.9)                                 | –                        |
| Missing  | 0                                     | 0  | 0                        |
| Education setting                                      |                                       |  |                          |
| Specialist school (private/other e.g. charity funding) | –                                     | 28 (63.6)                                | 26 (35.1)                |
| Specialist school (state funded)                       | –                                     | 7 (16.3)                                 | 22 (29.7)                |
| Mainstream (state funded)                              | –                                     | 4 (9.1)                                  | 13 (17.6)                |
| Other  | –                                     | 3 (6.8)                                  | 8 (10.8)                 |
| Mainstream school with additional resource for SEND    | –                                     | 1 (2.3)                                  | 2 (2.7)                  |
| Mainstream (private)                                   | –                                     | 0  | 2 (2.7)                  |
| Missing  | –                                     | 1 (2.3)                                  | 1 (1.4)                  |
| Current working environment <sup>a</sup>               |                                       |  |                          |
| Community – home                                       | 300 (64.2)                            | –  | –                        |
| Community – special education centre                   | 299 (64)                              | –  | –                        |
| Community – mainstream education centre                | 272 (58.2)                            | –  | –                        |
| Child development or family centre clinic              | 237 (50.7)                            | –  | –                        |
| Outpatients  | 138 (29.6)                            | –  | –                        |
| Inpatients   | 79 (16.9)                             | –  | –                        |
| Other  | 36 (7.7)                              | –  | –                        |
| Missing  | 70 (14.9)                             | –  | –                        |

SEND, Special Education Needs and Disability.

a Participants could choose more than one option.

‘–’ indicates that the item was not a response option for that group of participants.

### Importance of a research study

The majority of respondents in all participant groups suggested that further research into standing frames was needed but one-quarter of education professionals were not sure, and their open-ended responses indicated that this was because they were not aware of the findings from existing standing frames research. Most respondents in each participant group thought that standing frames should be used for non-ambulant young people with CP, and 78.2% of health professionals believed that they are clinically effective.

There were mixed responses as to whether or not health and education professionals would agree to young people with CP ceasing standing frame use if there was good-quality evidence showing that standing frames were not beneficial. The open-ended responses indicated that health professionals do not believe that there is any point in continuing with ineffective interventions, but research demonstrating that that was the case would need to be supported by professional bodies. Other health professionals did not routinely use standing frames in their practice anyway and as such felt that the state of the research would not change their practice. Those who disagreed with, or were unsure about, stopping standing frame use, even if there was good-quality evidence to do so, cited reasons such as the importance of giving young people an opportunity for a change of position, not being confident enough to make the decision themselves, perceptions of benefits regardless of evidence, and difficulty persuading parents to stop anyway. Many health professionals also commented that there would need to be evidence that standing frames caused harm, not simply that there were no benefits; the research would need to be extremely robust and conclusive. Education professionals also noted that there was no need to continue an intervention, such as a standing frame, if it proved not to be beneficial, but they would primarily follow advice from their health professional colleagues (e.g. physiotherapists). Others did not agree or were unsure because they felt that the young person's preference and individual needs, rather than research evidence, should dictate standing frame use. Professional experience was in support of the positive effects of a change of position through standing frame use.

Most respondents indicated that young people  $\leq 11$  years of age were most suitable to be recruited to standing frame research. Approximately half of each professional group said they would be willing to change their standing frame practice for a research trial compared with 63.6% of parents. It was considered acceptable by most participants to suspend or delay standing frame use for up to 12 weeks (Table 19).

**TABLE 19** Perceptions regarding the importance of a standing frame research study

| Perception   | Health professionals,<br>n (%) | Education professionals,<br>n (%) | Parents,<br>n (%) |
|--|--------------------------------|-----------------------------------|-------------------|
| Standing frames should be used for children with CP GMFCS III–V    |                                |                                   |                   |
| Yes  | 415 (88.9)                     | 34 (77.3)                         | 62 (83.8)         |
| No   | 2 (0.4)                        | 0 (0)                             | 1 (1.4)           |
| Did not know   | 12 (2.6)                       | 2 (4.5)                           | 6 (8.1)           |
| Missing  | 38 (8.1)                       | 8 (18.2)                          | 5 (6.8)           |
| I personally believe that standing frames are clinically effective |                                |                                   |                   |
| Yes  | 365 (78.2)                     | –                                 | –                 |
| No   | 8 (1.7)                        | –                                 | –                 |
| Did not know   | 56 (12)                        | –                                 | –                 |
| Missing  | 38 (8.1)                       | –                                 | –                 |

**TABLE 19** Perceptions regarding the importance of a standing frame research study (*continued*)

| Perception   | Health professionals,<br>n (%) | Education professionals,<br>n (%) | Parents,<br>n (%) |
|--|--------------------------------|-----------------------------------|-------------------|
| Further research into standing frames is necessary   |                                |                                   |                   |
| Yes  | 400 (85.7)                     | 26 (59.1)                         | 62 (83.8)         |
| No   | 3 (0.6)                        | 0                                 | 1 (1.4)           |
| Did not know   | 29 (6.2)                       | 11 (25)                           | 6 (8.1)           |
| Missing  | 35 (7.5)                       | 7 (15.9)                          | 5 (6.8)           |
| I would agree to change my practice for a research study   |                                |                                   |                   |
| Yes  | 237 (50.7)                     | 23 (52.3)                         | 35 (63.6)         |
| No   | 26 (5.6)                       | 6 (13.6)                          | 1 (1.8)           |
| Did not know   | 154 (33)                       | 5 (11.4)                          | 18 (32.7)         |
| Missing  | 50 (10.7)                      | 10 (23.7)                         | 1 (1.8)           |
| If there was good-quality evidence that standing frames were not beneficial, I would agree for children with CP to stop using them |                                |                                   |                   |
| Yes  | 159 (34)                       | 21 (47.7)                         | –                 |
| No   | 35 (7.5)                       | 4 (9.1)                           | –                 |
| Did not know   | 221 (47.3)                     | 10 (22.7)                         | –                 |
| Missing  | 52 (11.1)                      | 9 (20.5)                          | –                 |
| Suitable age groups (years) for a standing frames research study <sup>a</sup>  |                                |                                   |                   |
| 0–5  | 341 (73)                       | 18 (40.9)                         | 42 (56.8)         |
| 6–10   | 363 (77.7)                     | 26 (59.1)                         | 49 (66.2)         |
| 11–15  | 248 (53.1)                     | 18 (40.9)                         | 37 (50)           |
| 16–18  | 151 (32.3)                     | 12 (27.3)                         | 28 (37.8)         |
| No age groups are suitable   | 4 (0.9)                        | 3 (6.8)                           | 0                 |
| Missing  | 51 (10.9)                      | 9 (20.5)                          | 11 (14.9)         |
| Longest possible time to delay/suspend standing frame use (weeks)  |                                |                                   |                   |
| < 2  | 21 (4.5)                       | –                                 | 10 (18.2)         |
| 2–6  | 117 (25.1)                     | –                                 | 13 (23.6)         |
| 7–12   | 76 (16.3)                      | –                                 | 7 (12.7)          |
| 13–18  | 20 (4.3)                       | –                                 | 1 (1.8)           |
| 19–24  | 12 (2.6)                       | –                                 | 0                 |
| > 24   | 10 (2.1)                       | –                                 | 0                 |
| It is not appropriate to delay or suspend use of a standing frame for a research study   | 27 (5.8)                       | –                                 | 7 (12.7)          |
| Did not know   | 49 (10.5)                      | –                                 | 14 (25.5)         |
| Other  | 68 (14.6)                      | –                                 | 0                 |
| Missing  | 67 (14.3)                      | –                                 | 3 (5.5)           |

<sup>a</sup> Participants could choose more than one option.

‘–’ indicates that the item was not a response option for that group of participants.

### Feasibility of a research study

Over 55% of health professionals suggested that they would be willing to recruit participants to a standing frames trial, although only 22% thought that they would have time to do this in their current role and only 19% currently have good clinical practice training (*Table 20*). Open-ended responses indicated that health professionals who were willing to recruit participants in principle believed in the importance of research, were happy to be of help and were interested and/or invested in the topic. Those who were not willing or were unsure cited reasons such as time limitations; case loads (including heavy case loads and case load mix) and/or professional roles (e.g. believing young people on their case load would be too young or old to take part in a research study); the need for team support and/or decisions; perceived reluctance from parents and other staff; and the need for more information about the study.

**TABLE 20** Health professionals' perceptions regarding the feasibility of a standing frames research study

| Perception  | Health professionals, <i>n</i> (%) |
|---|------------------------------------|
| Appropriate person to recruit participants <sup>a</sup>                                       |                                    |
| Physiotherapist   | 383 (82)                           |
| Occupational therapist  | 65 (13.9)                          |
| Therapy assistant or technical instructor   | 106 (22.7)                         |
| Paediatrician   | 95 (20.3)                          |
| Orthopaedic surgeon   | 81 (17.3)                          |
| I do not know   | 5 (1.1)                            |
| Other (please specify)  | 22 (4.7)                           |
| Missing   | 72 (15.4)                          |
| In principle, I would be willing to recruit participants                                      |                                    |
| Yes   | 261 (55.9)                         |
| No  | 43 (9.2)                           |
| I do not know   | 89 (19.1)                          |
| Missing   | 74 (15.8)                          |
| In reality, I could recruit participants  |                                    |
| Yes   | 195 (41.8)                         |
| No  | 63 (13.5)                          |
| I do not know   | 135 (28.9)                         |
| Missing   | 74 (15.8)                          |
| I would have time to recruit participants to a research study in my current role              |                                    |
| Yes   | 102 (21.8)                         |
| No  | 112 (24)                           |
| I do not know   | 177 (37.9)                         |
| Missing   | 76 (16.3)                          |
| I have relevant clinical training which allows me to consent participants to a research study |                                    |
| Yes   | 89 (19.1)                          |
| No  | 246 (52.7)                         |
| I do not know   | 62 (13.3)                          |
| Missing   | 70 (15)                            |

**TABLE 20** Health professionals' perceptions regarding the feasibility of a standing frames research study (*continued*)

| Perception   | Health professionals, <i>n</i> (%) |
|--|------------------------------------|
| I would be prepared to do relevant training which allows me to consent participants to a research study <sup>b</sup> |                                    |
| Yes  | 188 (61)                           |
| No   | 37 (12)                            |
| I do not know  | 83 (26.9)                          |
| Missing  | 0                                  |
| I would be prepared for a research physiotherapist to be involved in the child's care for the duration of the study  |                                    |
| Yes  | 322 (69)                           |
| No   | 19 (4.1)                           |
| I do not know  | 47 (10.1)                          |
| Missing  | 79 (16.9)                          |

<sup>a</sup> Participants could choose more than one option.

<sup>b</sup> Percentages are calculated out of 308. That is, the number of participants who responded 'no' or 'I do not know' to the question 'I have relevant clinical training which allows me to consent participants to a research study'.

Health professionals who indicated that they could recruit participants thought that they had appropriate case loads and could persuade parents to participate, had previously been involved in research, and believed in the importance of research. Those who thought that they could not recruit participants did not have appropriate case loads, lacked time, or did not think that they could convince parents to take part. Health professionals who were unsure whether or not they could actually recruit participants for a trial gave reasons such as the decision would not be made by them (e.g. management would have to choose whether or not to take part), it would depend on the time commitment, limited resources, inappropriate work setting, changing professional roles, and perceptions that the families they work with would not be willing to take part.

More than half of the education professionals would be happy for young people at their school to take part (regardless of their allocation to an intervention or control group), would agree to a research physiotherapist visiting the school, and would find it easy to keep a diary of standing frame use, bowel functions, medications and pain.

Table 21 shows that although only 43% of parents expressed a willingness in principle for their child to take part in a research study regardless of their allocation, 25.7% were unsure. Open-ended responses indicated that parents who were willing believed that there was no negative difference between intervention and control groups, the study findings would benefit their child anyway by contributing to knowledge about young people with CP, and their child prefers not to use a standing frame over summer anyway. Those who would not be willing to have their child randomised (13.5%) or were unsure (25.7%) cited the following reasons: needing more information about the study, their child's tolerance and/or pain, fear of putting their child at risk, going against advice they have received, belief in the benefits of standing frames, uncertainty about what interventions the control group would receive and their child did not currently use a standing frame anyway. Similar to education professionals, parents reported that they would find it relatively easy to keep research diaries.

Parents were also willing to be approached by health professionals about a standing frame research study (64.9%), as well as to provide medical information (71.6%), to complete questionnaires (66.2%) and to have detailed physiotherapy assessments (66.2%) of their child (Table 22).

**TABLE 21** Education professionals' and parents' perceptions regarding the feasibility of a standing frames research study

| Perception   | Education professionals, <i>n</i> (%) | Parents, <i>n</i> (%) |
|--|---------------------------------------|-----------------------|
| I would be happy for children at my school/my child to take part regardless of whether or not they were in the experimental or control group |                                       |                       |
| Yes  | 25 (56.8)                             | 32 (43.2)             |
| No   | 2 (4.5)                               | 10 (13.5)             |
| I do not know  | 4 (9.1)                               | 19 (25.7)             |
| Missing  | 13 (29.5)                             | 13 (17.6)             |
| I would agree to a research physiotherapist visiting children at school for assessments  |                                       |                       |
| Yes  | 27 (61.4)                             | –                     |
| No   | 0                                     | –                     |
| I do not know  | 3 (6.8)                               | –                     |
| Missing  | 14 (32.6)                             | –                     |
| Keeping a daily diary of standing frame use would be   |                                       |                       |
| 1 (impossible)   | 2 (4.5)                               | 7 (9.5)               |
| 2  | 1 (2.3)                               | 7 (9.5)               |
| 3  | 2 (4.5)                               | 7 (9.5)               |
| 4  | 8 (18.2)                              | 12 (16.2)             |
| 5 (easy)   | 17 (38.6)                             | 26 (35.1)             |
| Missing  | 14 (31.8)                             | 15 (20.3)             |
| Keeping a detailed diary of bowel functions, medication and pain would be  |                                       |                       |
| 1 (impossible)   | 3 (6.8)                               | 4 (5.4)               |
| 2  | 2 (4.5)                               | 7 (9.5)               |
| 3  | 5 (11.4)                              | 13 (17.6)             |
| 4  | 11 (25)                               | 13 (17.6)             |
| 5 (easy)   | 9 (20.5)                              | 22 (29.7)             |
| Missing  | 14 (31.8)                             | 15 (20.3)             |
| Preferred method to keep a diary <sup>a</sup>  |                                       |                       |
| Electronic (e.g. iPad, phone, computer)  | 1 (2.3)                               | 13 (17.6)             |
| Hard copy (e.g. a book)  | 14 (31.8)                             | 20 (27)               |
| Either hard copy or electronic   | 10 (22.7)                             | 20 (27)               |
| I would not keep a diary   | 0                                     | 3 (4.1)               |
| Other  | 5 (11.4)                              | 3 (4.1)               |
| Missing  | 14 (31.8)                             | 15 (20.3)             |
| I would agree to work with a research physiotherapist  |                                       |                       |
| Yes  | 22 (20)                               | –                     |
| No   | 2 (4.5)                               | –                     |
| I do not know  | 6 (13.6)                              | –                     |
| Missing  | 14 (31.8)                             | –                     |

**TABLE 21** Education professionals' and parents' perceptions regarding the feasibility of a standing frames research study (*continued*)

| Perception   | Education professionals, <i>n</i> (%) | Parents, <i>n</i> (%) |
|--|---------------------------------------|-----------------------|
| It would matter if children in the same class were in different groups for the research study  |                                       |                       |
| Yes  | 2 (4.5)                               | –                     |
| No   | 21 (47.7)                             | –                     |
| I do not know  | 7 (15.9)                              | –                     |
| Missing  | 14 (31.8)                             | –                     |
| a Participants could choose more than one option.<br>'–' indicates that the item was not a response option for that group of participants. |                                       |                       |

**TABLE 22** Parents' perceptions regarding the feasibility of a standing frames research study

| Perception  | Parents, <i>n</i> (%) |
|---|-----------------------|
| I would be prepared to/for my child to be asked by a health worker if we would be interested in taking part in a research study |                       |
| Yes   | 48 (64.9)             |
| No  | 7 (9.5)               |
| I do not know   | 6 (8.1)               |
| Missing   | 13 (17.6)             |
| I would be prepared for me/my child to <sup>a</sup>   |                       |
| Provide medical information for the purpose of research   | 53 (71.6)             |
| Complete questionnaires about their participation and activities  | 49 (66.2)             |
| Allow them to have a detailed assessment by the research physiotherapist  | 49 (66.2)             |
| I would not agree to any of these   | 4 (5.4)               |
| Missing   | 14 (18.9)             |
| The best location for assessments during a research study would be <sup>a</sup>   |                       |
| School  | 40 (54.1)             |
| Home  | 38 (51.4)             |
| A clinic or centre where my child receives care usually   | 29 (39.2)             |
| A different clinic or hospital to where my child usually visits   | 13 (17.6)             |
| Missing   | 18 (24.3)             |
| a Participants could choose more than one option.   |                       |

### Barriers to a research study

The most common ethical reason identified by each participant group for not recruiting or participating in a standing frames research study was fear that stopping standing frame use could cause irreversible harm to the young person. Health professionals also reported that a research study would be too labour-intensive to be feasible (56.2%), whereas 29.5% of education professionals and 35.1% of parents did not believe any of the practical issues were applicable (*Table 23*).

**TABLE 23** Difficulties that would prevent survey respondents from recruiting to or participating in a standing frame research study

| Difficulties  | Health professionals, n (%) | Education professionals, n (%) | Parents, n (%) |
|---|-----------------------------|--------------------------------|----------------|
| <b>Practical<sup>a</sup></b>  |                             |                                |                |
| A research study would be too resource intensive to be feasible   | 129 (27.6)                  | –                              | –              |
| A research study would be too labour intensive to be feasible   | 150 (56.2)                  | –                              | –              |
| Children with CP are individual. It is impossible to research the impact of standing frames   | 44 (9.4)                    | 4 (9.1)                        | 1 (1.4)        |
| Some benefits of standing frames cannot be measured (e.g. 'feeling tall')   | 107 (22.9)                  | 8 (18.2)                       | 6 (8.1)        |
| It would be too difficult to get children and parents to participate in a research study  | 79 (16.9)                   | 0                              | –              |
| It would be too difficult to get professionals to participate in a research study   | 41 (8.8)                    | –                              | –              |
| I would not have the support in my workplace to take part in a research study   | 64 (13.7)                   | –                              | –              |
| There would not be enough space for children's standing frames  | –                           | 0                              | 7 (9.5)        |
| Other   | 76 (16.3)                   | 7 (15.9)                       | 21 (28.4)      |
| None of these apply   | 0                           | 13 (29.5)                      | 26 (35.1)      |
| Missing   | 141 (30.2)                  | 18 (40.9)                      | 20 (27)        |
| <b>Ethical or personal choice<sup>a</sup></b>   |                             |                                |                |
| It is not right to withdraw standing frame treatment for a research study   | 51 (10.9)                   | 3 (6.8)                        | 6 (8.1)        |
| Stopping standing frame use for a research study could cause harm that could not be reversed  | 186 (39.8)                  | 13 (29.5)                      | 16 (21.6)      |
| Participating in a research study about standing frames may affect the child's quality of life negatively   | 102 (21.8)                  | 6 (13.6)                       | 4 (5.4)        |
| The child's choice, rather than a research study, should dictate their standing frame use   | 107 (22.9)                  | 7 (29.5)                       | 7 (9.5)        |
| I would feel guilty if I could not do everything I needed to do for the study   | –                           | –                              | 14 (18.9)      |
| It is an emotionally significant moment to see my child stand; it is more important to me than a research study                                       | –                           | –                              | 2 (2.7)        |
| Other   | 55 (11.8)                   | 2 (4.5)                        | 10 (13.5)      |
| None of these apply   | 0                           | 9 (20.5)                       | 19 (25.7)      |
| Missing   | 164 (35.1)                  | 18 (40.9)                      | 22 (29.7)      |
| <sup>a</sup> Participants could choose more than one option.<br>'–' indicates that the item was not a response option for that group of participants. |                             |                                |                |

**What does survey 2 add?**

Survey 2 demonstrated that the majority of participants believe that more standing frames research is necessary. Most respondents suggested that they were willing in principle to engage in a trial. For example, most parents were willing to be approached by health professionals about participating in a research study, have their child randomly allocated to experimental or control groups and change how their child uses a standing frame for the purposes of a research study. Furthermore, approximately 50% of health and education professionals would agree to change their standing frame practice for a research study.



In addition, the results of survey 2 provided vital information about 'deal breakers' in a standing frames research study. The maximum amount of time most health professionals and parents would agree to suspend/delay standing frame use is 12 weeks. There are factors that would stop a relatively small proportion of professionals and parents participating in a standing frames study, such as fear, that suspending use would cause irreversible damage. Although these may not appear to be major issues at this stage, they are important factors for consideration when calculating the number of potential participants that would need to be approached.

Survey 2 has also showed that stakeholders have different perceptions regarding challenges to a research study. Feasibility is a major issue. For example, a higher proportion of health professionals than parents indicated that there were issues that would stop them recruiting for, or participating in, a study. Health professionals are clearly invested in standing frames, and education and resource may be required to enhance engagement in a research study.

### **How has survey 2 informed the next step?**

Survey 2 allowed us to see if the discussions in our qualitative work were generalisable to a wider population. It also enabled us to explore 'deal breakers' in a trial for potential participants.

Large numbers of data were collected throughout the study. It was essential to record, analyse and share this information in order to understand it. Therefore, the next phase of the study was engaging stakeholders in sense checking and interpreting the findings. A secondary outcome of this was engagement of potential future participants and dissemination of findings.

Analysis of the results led the co-applicants to consider and ask stakeholders the following questions in two design workshops (see *Chapter 8*):

- What are the research priorities as related to standing frames?
- What are the pros and cons of different research study designs?
- Should a standing frames research trial be explanatory or pragmatic?



# Chapter 8 Robustness of results: stakeholder involvement and patient and public involvement

## Objectives

The collated study results (survey 1, single stakeholder focus groups, interviews, multistakeholder focus groups, survey 2) were taken to two multistakeholder design workshops in June 2017. The aims of these design workshops were to discuss (1) the study's findings, (2) priorities for research studies, (3) potential trial designs and (4) produce conclusions and recommendations. Potential research designs that were discussed were (1) standing frame use versus no standing frame use and (2) treatment as usual standing frame use (i.e. participants would continue to use their standing frame as they usually would) versus 'super standing' [i.e. extra support provided to use the standing frame as generally prescribed (five times per week for 30–60 minutes)]. The design workshops were also to ensure that the results were robust and the co-applicants' ideas were staying true to the data.

Attendees at the design workshops included co-applicants, steering group members and various stakeholders, such as physiotherapists, orthopaedic surgeons, paediatricians, parents and a young person with CP. Stakeholders were identified through the PPI group, clinical connections or participants who had expressed interest and consented to further contact either via the survey or after the focus group. Three of the physiotherapists had been focus group attendees but none of the other stakeholders had taken part in a focus group. A medical professional who was naive to the study took notes on the discussion. Jill Cadwgan and Jane Goodwin were particularly mindful not to lead the conversation based on their own biases because they had been immersed in the data from the outset and throughout. The discussions are summarised here.

## Design workshop: various stakeholders

Co-applicants Jill Cadwgan, Allan Colver, Anna Basu, Denise Howell, Sarah Crombie, Jan Lecouturier and Johanna Smith were in attendance, along with a member of the steering group (paediatrician), five physiotherapists and an orthopaedic surgeon.

## Research priorities

A detailed discussion of research priorities revealed that participation should be a primary outcome with body function as a secondary outcome. That is:

1. Primary outcome: quality of participation (including, but not necessarily limited to, interaction, communication, vision, using upper limbs/motor abilities). Related to this, it is important to examine what elements of participation are associated with being upright.
2. Secondary outcome: body function (including, but not limited to, bowel function, speech, breath control, feeding).

Throughout this, it would be important to ensure that everyone involved understands the concepts of evidential and emotional equipoise. It would also be important to shift from the value of body structure to the importance of participation. Both of these would require significant education for professional and parent stakeholders.

### ***Trial design***

In principle, it was agreed that a trial would need to be pragmatic rather than explanatory. Intervention versus no intervention was preferable to standing versus an increased dose of standing because of the perception that it would be impractical and prohibitively expensive to introduce 'super standing'. Furthermore, it would be more difficult to show a significant difference between two slightly different doses. Useful comparators include walkers, standing slings, supported lying positioning and powered chairs. A qualitative component would be required to adequately capture experiences. However, any type of research study in this population would require significant resources, even to facilitate adherence to the prescribed standing frame use. Therefore, trial settings (e.g. specific specialist schools) and stakeholder engagement would need to be established as early as possible.

### ***Reservations about a trial***

Design workshop attendees had several reservations about a standing frames research study. Some major concerns centred on the ethics of conducting research that may demonstrate standing frames do not achieve certain outcomes. This has implications for commissioners, and there were fears that standing frames may not be funded in future, even though many families and young people with CP enjoy using their standing frames (regardless of any body structure, body function, participation or activity benefits). Some people have such strong beliefs about the benefit of standing frames on the body that they are likely to continue to use them, despite any evidence that is produced. Commercial companies are likely to continue to market their products as helpful for body structure, and this may have more of an influence on professionals and families than the results of a scientifically robust research study. Furthermore, the intrinsic perception regarding the body structure benefits of standing is difficult to overcome because it is virtually impossible to design research that isolates the impact of standing frames alone.

The design workshop highlighted a number of topics for discussion. The importance of clinically relevant outcomes was raised. For example, is bone density worthwhile exploring if it does not affect the risk of fractures? Exploring the idea of reducing sedentary time and increasing metabolic rate may also be worthwhile. The physiotherapists were particularly concerned that a research study (and potential findings) could increase parental guilt and create additional practical difficulties. If participation outcomes are being measured, the standing frame should be used to access existing activities, not new activities, because otherwise we will be enhancing participation by default.

### ***Design workshop: parents***

A second design workshop was held with five parents and one young person who uses a standing frame because we were unable to get representation from these groups at the first workshop. It was facilitated by co-applicant Johanna Smith and research associate Jane Goodwin. The aims were the same as the first workshop, and the discussions from the day are summarised here. It is important to note that parents were reacting to the information given to them on the day from a lay perspective; therefore, some of their ideas had previously been explored. The summary reports the parents' views only, and we have not further justified and analysed them in this section. However, these ideas have contributed to the final recommendations in *Chapter 9* in combination with the synthesis of all the results of the study.

### ***Research priorities***

Parents suggested that the research priority should be the change of position that comes with standing frames, because they believe that it gives their child access to, for example, eye contact, general participation and life in a different position:

- Primary outcome: change of position (including, but not necessarily limited to, access, stretch, comfort, functional ability, interaction, being like other young people and enjoyment).

- Secondary outcomes:
  - Physiological measures (including, but not limited to, bowel function and breathing). Parents believed that it was important to have a medical reason for using standing frames so that they could continue to use the standing frame for participation. They suggested that body structure/function and participation cannot be separated, and, as such, neither should be neglected. Parents also perceived that it would be easier to persuade schools to use standing frames if there was physiological science behind it, rather than simply parents' beliefs about what is best for their child.
  - Young person's quality of life (including, but not necessarily limited to, how the standing frame affects how they feel about themselves and being disabled, and their self-awareness). Parents commented that young people often realise in their teen years that their disabilities are permanent, and that this realisation can cause major psychological distress.

Parents also believed that standing frames research did not necessarily have to be about progress (e.g. improving function). It could be about maintaining existing skills or preventing any deterioration and this would be enough to justify the use of standing frames.

### **Trial design**

Attendees at this workshop had alternative suggestions for standing frame research designs. For a study regarding change of position, they recommended monitoring young people to see how much they get to move. Parents believed that there was an evidence base for the health benefits of changing positions. They also suggested a retrospective study could be conducted with older young people, investigating body structure outcomes (e.g. bone density) then examining their medical records to see how much they had used their standing frame. Finally, parents proposed conducting a study with a group of young people who do not already use a standing frame and have them use one for 12 weeks to see the results. This way, nobody 'loses out' on using a standing frame. Some of these ideas are not likely to be feasible (discussed in *Chapter 9*) or scientifically robust, and as such highlight the need to educate families at recruitment about the trial's research priorities and methods.

They suggested sit-to-stand wheelchairs (which allow the young person to keep up with friends and siblings without manual lifting) as a potential comparator.

### **Pros and cons of trial designs**

Parents generally agreed that 12 weeks was acceptable for delaying or suspending standing frame use, especially if the study was built into the school holidays. However, one parent commented on the struggle between wanting research and her child's individual needs. She is desperate for research that might help her child but she would not feel comfortable withdrawing her child's standing frame for the purposes of a study because her child enjoys standing so much.

Parents were also worried about one of the potential trial designs presented to them. That is, standing treatment as usual versus 'super standing'. They did not think that it was right to introduce an intervention (such as an enhanced standing programme) then take it away, especially if the young person really enjoyed it. They would want a guarantee that the intervention would still be available after the research study. This would not be feasible in current UK practice according to our survey 1 results. Likewise, the parents expressed concern that if a young person is not used to standing five times per week, it may be a shock. However, the young person who attended the workshop indicated that it would be acceptable to stand that often. Another concern was the variability in function of young people with CP. Energy levels and muscle tone can vary on an hourly or daily basis and parents felt that as a result it would be difficult to determine what changes were caused by the standing frame use.

Parents had some recommendations for a research study with standing frames. First, it may be more feasible to do with younger children because it is physically easier and they can engage in activities like painting. Older young people find the use of a standing frame more difficult (especially at mainstream

schools) because of room changes, space and wanting to fit in with peers. It would be better to have young people participating in a research study standing at the same time in a classroom so that they can be the same as their peers. Lots of activities can be done in a group if everyone is in a standing frame.

### *Reservations about a trial*

Parents were 'disappointed with science'. They have learnt that health professionals use their best guess, and that parents receive anecdotal evidence (which is useful) from other families. It had been surprising and disappointing to learn about the lack of evidence for the many treatments their children undergo (e.g. postural management), even if they do make logical sense. Therefore, they do believe that there is a need for research, yet they worry that studies may demonstrate that standing frames have no clinical effect, which could mean they are no longer funded. This would be very distressing because many families believe that the standing frame is worthwhile, especially if their child enjoys using it. They wondered whether or not their child's enjoyment would count for anything with commissioners.

In terms of practicalities of a study, parents suggested that the best way to achieve compliance would be if it was carried out at school. It is asking a lot of parents to meet study requirements, such as standing five times per week. However, it is difficult for parents to know what is being done at school. They noted that the child receives a prescription for standing frame use which may be different from what is actually happening at school, and parents may not be included in any part of this process.

# Chapter 9 Discussion

## Introduction

The overall purpose of this study was to answer the question: what is the likely acceptability of a trial to determine the clinical effectiveness of standing frames? To do this, we undertook two surveys, focus groups and in-depth interviews.

## Summary of findings

The range of clinical indications and benefits described by all participants throughout the study included body structure and body function, such as bladder or bowel functions, activity, such as improved motor abilities, and participation, such as interaction with peers. They also reported other benefits, such as improvement in BMD and prevention of hip dislocation. They noted challenges related to environmental and personal factors such as physical space and the child's pain. With respect to body structure and body function, participants perceived benefits despite the lack of evidence in the literature. For example, 73.8% of prescribing clinicians in survey 1 (current UK standing frame practice) (see *Table 12*) reported a belief that frames improve bladder and bowel functions, yet we found only one single-case study in a child with CP and chronic constipation.<sup>26</sup> Furthermore, although using a standing frame to support hip joint development has some scant evidence, participants identified this as a benefit of standing frames. More research is needed for guidance on positioning, as well as the duration and frequency of standing.<sup>5</sup>

Participants also perceived standing frames to help with participation, enjoyment and communication. Physical assistance and environmental adaptations improve participation in children with CP,<sup>27</sup> but to our knowledge, there is no research relating specifically to standing frames. Being at standing height may be advantageous for social interaction and independence, but this is dependent on the position and activities of other individuals. When a person is using a wheelchair, a standing companion receives more eye contact from third parties, giving the impression that the wheelchair user depends on their standing companion.<sup>28</sup> In terms of activity, upper limb function can be affected by positioning. Self-feeding may be enhanced by standing, but picking up small objects is easier if sitting.<sup>29</sup> The young people with CP who were interviewed (*Chapter 5*) also commented on the importance of independence. Young people have previously reported that independence is essential for self-sufficiency and making choices.<sup>30</sup> Some young people in the current study thought that the standing frame limited their mobility and independence because they had to rely on others for help while in the standing frame. Static standing frames take away the young person's ability to move freely and can isolate them from their peers. Therefore, they preferred their powered wheelchairs. This is similar to previous research that highlighted the positive effect of powered wheelchairs in terms of social activities and being able to engage in the environment without constant supervision and assistance from others.<sup>31</sup> However, others thought that their standing frame allowed them to participate more in activities such as cooking.

There are significant challenges with regards to standing frame use. Participants in survey 1 (current UK standing practice) and the qualitative studies identified physical space as a particular difficulty. Huang *et al.*<sup>32,33</sup> also found space to be a major factor restricting assistive device use (including standing frames) by parents and teachers in their study in Taiwan. Other barriers in their study included inadequate teacher training and personal factors such as feeling pressured to use equipment at school but not at home.<sup>32</sup> Huang *et al.*<sup>32,33</sup> did not report on carer availability for moving and handling, which was a reported difficulty in our study.

## What have we found?

The results from survey 1 (UK standing frame practice) and the focus groups, along with discussions at design workshops and PPI events, showed that standing frames are largely prescribed to ameliorate difficulties or potential difficulties of body structure and body function. Other benefits (e.g. participation and activity) are considered to be useful by-products rather than primary aims. Despite the lack of supporting evidence, the majority of stakeholders have strong beliefs about the benefits for body structure and body function. Prescription is based on clinical experience and pragmatism.

Thus, there is not universal emotional equipoise about whether or not standing frames work.

### *What would not be feasible in a trial?*

Despite the emphasis on body structure and body function in the prescription and use of standing frames, we found that body structure outcomes would be challenging as the focus of a trial. We outline the reasons for this view:

- Timelines: responses from parents and professionals suggest that 12 weeks is the maximum amount of time they would delay starting or withdrawing standing frame use. An intervention would need to be longer than this to have an effect on body structure.
- Carry over effects: although a crossover study was used as a potential study design for survey 2, it was decided (based on co-applicant discussions and the design workshops) that this was impractical because of carry over effects.
- Co-interventions: standing frames are just one aspect of young people's postural management. Other health and therapeutic interventions, such as walkers, are likely to impact on the same outcomes that standing frames might influence. Co-interventions would also be problematic in a trial with a short intervention period and long-term follow-up.
- Type of standing frame/position: as a result of the different types of standing frames and positioning within them, there are too many variables which may impact on the outcome being measured, such as bone density. For example, prone standing may provide a different level of weight bearing compared with being upright.

### *What might be feasible in a trial?*

If young people are not being prescribed standing frames, or are not using their standing frames solely to improve body structure, we should examine the other indications for use that have been identified in our study. That is, body functions (e.g. bowel function) and other benefits (e.g. choice, change of position, participation, enjoyment and communication).

These 'other benefits' are broad, including aspects of quality of life, participation and subjective well-being, and could be explored in a trial as patient-reported outcomes. The World Health Organization defines 'quality of life' as an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.<sup>34</sup> It is a broad-ranging concept, affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment. Participation is involvement in a life situation<sup>19</sup> and subjective well-being is self-reported well-being, including happiness, pleasure and fulfilment.

To the authors' knowledge, there is no published research into the clinical effectiveness of standing frames with respect to patient-reported outcomes. A potential study design is proposed in *Chapter 10*.



## Limitations of our study

It is likely that the study attracted participants who were interested, engaged and had strong opinions, whether positive or negative, about standing frames. Therefore, they may not be representative of the general population of people who work with standing frames, have a child who uses or has used a standing frame, or of young people who use standing frames. A limitation of the parent groups was that their children had all used a standing frame for a number of years. We were not able to explore views on delayed start with parents who were within a year or two of diagnosis when that could be an option.

Furthermore, because of the nature of recruitment and the anonymity of surveys 1 and 2, we could not calculate response rates or determine non-response bias. There were also challenges in engaging education staff and parents. It is likely that education staff were difficult to recruit for face-to-face events (e.g. focus groups) because there are no other people to cover their duties during the day and after school hours they have further work and personal commitments. This reflects what we would anticipate in trial. Therefore, a trial would need to specifically target schools for recruitment and arrange the study in a way that was acceptable to and convenient for education staff. Parents were also hard to recruit for face-to-face events, with many cancelling just prior to the focus group. This is not surprising because they have significant caregiving responsibilities. Therefore, the education staff and parents who were able to participate in the Understanding Frames study may not be representative of the underlying populations.

Professionals' experiences of standing frames may be coloured by a variety of factors including their training, the region of the UK they work in, and the population of young people they work with. As the study progressed, we realised that education professionals would be major stakeholders in a trial. Therefore, it would have been helpful to have a separate survey 1 for this participant group to give more information on use of standing frames within the school context, which would have been useful considering the proposed trial within the school context. Parents' experiences are likely to be influenced by demographic factors (e.g. socioeconomic factors), their emotional journey with having a child with CP, the support they receive, and the way their child reacted (and continues to react) to their standing frame use.

In terms of participation in research, different factors may influence parents and young people. This has been highlighted in our current study and is relevant in future trials. For example, depending on their level of education a visit to a university may be intimidating, or, as a result of previous experiences, hospital visits may be upsetting. Lack of interest in research, time to participate and the priority of the research question in relation to the family's own interests and priorities are also important factors to consider. The young people's experiences may be affected by their cognitive and communicative abilities. Although we aimed to include participants with a variety of experiences and abilities, the sample is more representative of young people with CP who have the capacity to provide assent, and understand relatively complex questions about their standing frame use. Five out of the 12 participants attended mainstream school (including one mixed placement), and only one participant used a VOCA. Although the qualitative findings may not be representative of all standing frame stakeholders, they contribute to the body of knowledge surrounding young people, CP and standing frames, by highlighting both positive and negative impacts on these participants.

## Strengths of our study

We received rich data from a variety of stakeholders. Mixed methods has given us confidence in our research findings because of the holistic examination. Data from survey 1 (current UK standing frame practice) informed us of the wide range of perceived benefits and challenges to standing frame use, but in-depth understanding of these could only be extracted during the focus groups and interviews. Young people in particular added understanding of the complexities of how using frames may affect participation, activity, interaction and emotional well-being. Survey 1 also contributed to our understanding of study designs (e.g. delayed or suspended use) that could be explored in the qualitative phase of the study.

Ideas produced in the qualitative stage gave us priorities for research and potential trial designs. The qualitative aspect allowed for in-depth examination of what was acceptable for various stakeholders and the reasoning for their comments. Final feasibility of these trial designs was then tested in a wide population through survey 2 (research trial acceptability and feasibility). The benefits of mixed-methods design have been outlined in *Chapter 2*.

There were a large number of survey participants from all over the UK. We had representation from professionals who work in a variety of settings. We also had strong PPI from the outset and throughout. PPI advisory group members (as well as informal PPI) provided feedback on the initial application, study documents (e.g. information sheets), surveys (1 and 2), potential trial designs, the co-applicants' interpretation of the data and dissemination. Furthermore, having a parent of a young person with CP on the co-applicant team was a great strength of this study. The PPI allowed the research to be grounded in the practicalities of conducting research with families affected by CP (e.g. holding focus groups in the middle of the day because of commitments before and after school hours, allowing time for introductions to make parents more comfortable), as well as remaining accessible (e.g. avoiding overloading participants with information) and respectful (e.g. type of language used).

# Chapter 10 Conclusions

## Recommendations for research

### *Current research priorities*

We found that patient-reported outcomes (e.g. quality of life, participation and subjective well-being) are important to young people, parents and professionals (both health and education professionals) and feasible for a trial with a short intervention. This was recognised in each stage of the study, particularly the design workshops held after the study data had been collated. Body structure and body function characteristics are also important and would be of interest to a variety of stakeholders, but we found they would be difficult to use as primary outcomes. We have proposed body structure as a secondary outcome. Despite the clinical impression that long-term effects on body structure (e.g. bone density and preventing the need for surgery) may take several years to evaluate, our study showed that parents and professionals are worried that harm may occur from not using a standing frame relatively quickly (e.g. loss of joint range of movement over a summer holiday). Using body structure as a secondary outcome would allow any harms to be identified.

We recommend trials that focus on the following outcomes:

- Primary outcome:
  - selected from patient-reported outcomes (e.g. participation).
- Secondary outcomes:
  - patient-reported outcomes not included as a primary outcome (e.g. quality of life, subjective well-being)
  - body function (e.g. bowel function, speech, breath control and feeding)
  - body structure (e.g. loss of range of movement).

### *Recommendation of, and rationale for, particular trial designs*

We recommend a mixed-methods design. A qualitative process evaluation alongside the quantitative data collection could help understand the complexity of the intervention and social contexts, and the clinical effectiveness of the intervention.<sup>35</sup> Qualitative data could also capture the experience of young people when they are (or are not) using standing frames, as well as all stakeholders involved in standing frame use.

As we found that 'prescribed' standing frame use was generally not achieved because of a variety of factors, a trial should be pragmatic (i.e. able to work in everyday practice) rather than explanatory (i.e. work in ideal circumstances). Survey 1 (current UK standing frame practice) and focus group results showed that physiotherapists were not monitoring as often as they would have liked to because of lack of resources. Therefore, a trial should also include a health economic evaluation.

We present our recommendations for a research trial using the PICOTS framework.

### **Population: young people with cerebral palsy (Gross Motor Function Classification System III–V)**

A study in those children of infant and primary school age (4–11 years) is likely to be the most practical with respect to ease of facilitation of standing frame use in school, size of standing frames and the typical age at which most young people with CP start using standing frames. A study with preschool children was considered, but we decided against it because of such factors as the developmental age of the child and preparedness of families to be recruited to a trial when their child had been recently diagnosed with CP (as advised by parent participants and co-applicant Johanna Smith reflecting on their past experiences). Using standing frames at secondary school age, particularly in school, is a challenge because of environmental considerations, and young people and professionals may be less able to adhere to a trial protocol.

The commissioned call suggested research into young people with CP GMFCS IV and V; however, our survey shows that standing frame use in younger people with GMFCS III is widespread, in keeping with our clinical experience, and we therefore recommend that inclusion criteria should include young people with CP GMFCS III. Classification of young people on the basis of their pattern of motor impairment (e.g. dystonia vs. spasticity vs. mixed) would be difficult because it is clinically difficult for clinicians and parents to distinguish. Both boys and girls should be included. Data capture for the current study was predominantly in England, but there is no reason why study sites in Scotland, Wales and Northern Ireland should not be included.

### **Intervention: standing frame use (3 days per week)**

We found that recommended standing frame use was 30–60 minutes daily for 5 days or more each week, but that this was not usually achieved. Pragmatically, a standing frame intervention for a duration tolerated (for longer or shorter periods) by the young person for 3 days per week would be an appropriate dosage based on the results from survey 1 (UK standing frame practice).

Adherence to a trial regime greater than this would be likely to require significant resource to ensure implementation and may be susceptible to reduced compliance and fidelity. Some young people use standing frames at home, and there would need to be consideration of a standardisation of standing frame use at home.

Many types of standing frames are used and prescription should be appropriate to the individual young person. Because the primary outcome will be selected from patient-reported outcomes (e.g. participation), the specific type of standing frame is less important. It would be unfeasible to recommend exactly which standing frame the young person should use. More important is consideration of the suitability and availability of the standing frame to the individual child. Angle and position may need to be considered and could be examined in the qualitative component of the trial. For example, if a young person is looking up in the air or down at the floor, participation and activity may be more limited.

### **Comparator: no standing frame use**

Standing frame use versus no use, or versus alternative therapy or equipment (e.g. hydrotherapy or disability exercise bike) has been discussed in detail throughout the study. Consensus suggests that standing frame use versus no use would be most likely to detect change and be feasible. All young people would be likely to have other therapy, orthotics and activities regardless of whether they were in the intervention or non-intervention group ('treatment as usual') but randomisation should lead to a balance with respect to these factors across trial groups. Careful consideration of trial design will be necessary in order to control for these, or to define and standardise 'treatment as usual' for the duration of the trial. This may be a consideration for the final population or setting; for example, control of 'treatment as usual' may be easier in one particular location or setting.

**Outcomes:** selected patient-reported outcomes (e.g. quality of life, participation, subjective well-being), body function and structure

- Primary outcome:
  - selected patient-reported outcome (e.g. participation).
- Secondary outcomes:
  - patient-reported outcomes not included as a primary outcome (e.g. quality of life, subjective well-being)
  - body function (e.g. bowel function, speech, breath control and feeding)
  - body structure (e.g. loss of range of movement).

Measures should address the primary and secondary outcomes of the study. Selected patient-reported outcome measures could assess quality of life, participation, and subjective well-being. All measures should ideally be adaptable to the young person's communication level and cognitive ability. There may be a need for parent- and/or education staff-proxy reports of the child's patient-reported outcomes (e.g. quality of life, participation and subjective well-being), although the ideal would be young people's self-report. It will also be important to assess impact on parents and family life. Secondary outcome measures of body function may include respiratory function, bowel function and pain, and of body structure may include clinical measures of joint range of movement and growth.

Adherence to trial protocol would need to be carefully monitored as our survey highlights that 'treatment as prescribed' is not always achieved. Both quantitative and qualitative methods should be included. This is particularly important when considering young people's voices and the individuality of standing frame prescription (i.e. what works for one child may not work for another, and quantitative research may not capture this variation).

### Timing: 6–12 weeks

We found through survey 1 and the qualitative work that young people often have a break from standing frame use during school holidays. Survey 2 demonstrated that suspending or delaying standing frame use would be acceptable and ethical for a period of 6–12 weeks. However, qualitative data from parents reflecting on their experiences revealed that delayed use (i.e. a waiting list control design) would not be an acceptable trial design. It must be noted, however, that we did not have any parent participants who had a child who had recently been diagnosed with CP to confirm whether or not a delayed start would be acceptable. Therefore, we recommend suspended use for 6–12 weeks. Furthermore, there may be other variables (e.g. other therapies and activities) that need to be taken into account in the school holidays compared with school term time.

Anxieties highlighted by stakeholders regarding deterioration in body structure for longer durations of 'non-use', could be alleviated by including clinical assessments at the time of the outcome assessments.

### Setting: specialist school environment

We recommend that standing frame use should be explored in the specialist school environment, because this is where most young people with GMFCS III–V are educated; furthermore, specialist schools would be better equipped to support standing frame use for the purposes of a trial, as they tend to be used in this environment anyway. There may be challenges with education, training and support of educational professionals in conducting a trial in that setting. Although our survey 2 data suggested that education staff would be willing, and find it acceptable, to recruit to a trial, our focus group data from a single specialist education school highlighted issues with staff confidence and achieving prescribed standing in a classroom because of conflicting interests between therapy and education. Furthermore, we experienced difficulties with education staff recruitment to both focus groups and the surveys, likely because they do

not have other people to cover their duties and they have other work and personal commitments. This may have implications for trial buy-in from education staff, and adherence to treatment as prescribed in the school setting.

For adequate statistical power, a trial would need multicentre recruitment. Describing, and potentially balancing or adjusting for 'treatment as usual' would need to be considered. For example, young people are more likely to receive a similar therapy or orthotic programme in one school, but these interventions are likely to vary between schools.

### **Potential challenges**

Our study identified significant challenges for a research trial but we believe that they are surmountable with careful planning. PPI (including young people with CP) would be required from the development of a funding application for a future trial through to the dissemination of the results. This level of PPI could be achieved by allowing members to take part flexibly (e.g. via online forums) and having representatives on the co-applicant team (parent and/or young person with CP) as well as on the Trial Steering Committee and/or a separate PPI RAG.

### **Recruitment and attrition**

Allied health professionals, particularly physiotherapists, were the main professional stakeholders (in terms of prescribing, monitoring, and supporting standing frame use) for standing frames. Physiotherapists would therefore be the most appropriate professionals to recruit participants.

We had problems finding education staff willing and able to participate in our study, which might mean there will be difficulties engaging schools in a full trial, although it is the preferable setting. However, for the purposes of our study, we were asking education staff to leave the school setting and participate in research that was beyond their role. If the setting for a trial was in a specialist school, education staff would be asked to position their students in a standing frame, which is something they often do anyway.

### **Consent and assent**

We found that young people with CP may have different opinions to their parents about their standing frame. This has implications for the young people's assent to a trial. Furthermore, if young people have strong feelings (positive or negative) about using a standing frame, their allocation to intervention or control could have a significant confounding effect on the outcome measures, including quality of life and subjective well-being. It would be important to note reasons for non-recruitment of screened population including lack of assent from the young person for trial. Legal and ethics frameworks around consent and assent would also need consideration.

### **Engagement in a trial**

We found that engagement of stakeholders in a trial may be challenging because of the emphasis currently placed on body structure. Professionals may be unaware of how their conversations with families may lead to families sharing the same views about frames. Shifting the framework to patient-reported outcomes (e.g. quality of life, participation and subjective well-being) and body function outcomes will require education to engage professionals and families in a trial and to inform thinking in clinical practice.

Moreover, young people with CP may have multiple comorbidities and/or general health issues which may prevent them from participating in a trial.

### **Need for equipoise**

In one sense standing frames work because they do make the young person stand. What we need to ask is 'what is the standing for?'. Professionals, parents and young people entering the trial should think that the trial is worthwhile because it is an open question whether or not standing frames have benefit. If they are certain of benefits, they may not consent to the trial. Personal preferences for standing frame use may thus affect recruitment.

## Implications for health care and the need for a pilot phase

Although there is no strong evidence that standing frames are beneficial, they still might be. We found that it will be difficult to develop a robust evidence base. We also found that many stakeholders (including physiotherapists, parents and young people) are invested in standing frames despite the paucity of evidence for their use. Therefore, standing frames may continue to be prescribed and used even if a future trial demonstrates that they are not effective with respect to selected patient-reported outcomes (e.g. quality of life, participation and subjective well-being) and body function. Participants suggested that there would need to be evidence that standing frames cause harm for people to stop using them.

For all of the above challenges identified, it is not feasible or cost-effective to progress to a full multicentre RCT. This leaves a question regarding the logical next step. There are two possibilities:

1. A randomised feasibility study – an external stand-alone pilot.
2. A randomised feasibility study – an internal pilot with clear progression criteria to a full trial.

We would recommend a randomised feasibility study (an internal pilot phase with clear progression criteria to a full trial), and summarise the reasons:

- To determine that physiotherapists have the capacity to recruit, especially for a trial in the specialist school setting.
- To explore the extent to which parents and professionals are agreeable to the primary outcome of a selected patient-reported outcome (i.e. participation). What people say they will do may be quite different from what they do when confronted with a real-life decision.
- To establish whether or not education staff in specialist schools are prepared to 'buy in' to the study, and to facilitate the prescribed standing programme.
- To establish that sufficient staff and families are in equipoise.
- To establish that the proposed outcomes can be collected.

The researchers considered a randomised feasibility study (an external stand-alone pilot), that is, data would be collected on the feasibility of a future trial (e.g. recruitment, retention and choice of outcomes), but would not be used in the definitive trial. However, they decided against it for the reasons summarised:

- It would be at least 8–10 years before any definitive conclusion about standing frames could be obtained. The current study has highlighted that families would value evidence about the benefits of standing frames as soon as possible, and may object to waiting for this amount of time.
- With recruitment and power concerns, data captured in a pilot would be valuable.
- A pilot would require much effort and commitment from staff, young people and parents. It might be considered unethical to then omit them from the main study if the design was feasible.

Therefore, there is a strong argument for an internal pilot (i.e. data collected at this stage would be included in a main trial). Although the internal pilot reduces waste, there would need to be consideration of how to manage the data collected if the trial design was adjusted to improve feasibility of the main trial.<sup>36</sup>

## Concluding statement

Our findings suggest that a trial could examine standing frame use in young people with CP GMFCS III–V. The primary outcome of the trial should be a selected patient-reported outcome (e.g. participation), with other selected patient-reported outcomes (e.g. quality of life, subjective well-being, body function and body structure) as secondary outcomes. There would be multiple factors to consider in the trial design including the heterogeneity of the population, significant challenges to recruitment and retention and adherence to protocol. These challenges can be overcome by clinical understanding of the population and careful trial



design to include a randomised feasibility trial (i.e. an internal pilot). Consideration of issues including knowledge of treatment as usual, other postural management approaches and outcome measures will be required. A mixed-methods approach, which captures quantitative and qualitative data about users' experience, is necessary.

Standing frames are one part of postural management for young people with CP GMFCS III–IV. Many of our findings are relevant to potential trials of many interventions for young people with neurodisability. We have shown that it is possible to obtain young people's views, which are highly valuable with respect to their engagement in clinical intervention and research.

Parents and professionals engaged in the qualitative aspect of this research, and stakeholders who took part in the design workshops understood the concept of evidential equipoise and appreciated the lack of clinical evidence. However, our surveys and qualitative information (and PPI) demonstrated that most people are not in a position of individual emotional equipoise and have strong beliefs regarding the clinical effectiveness of standing frames.

Despite the publication of the *International Classification of Functioning, Disability, and Health* in 2001 (and the ICF-CY in 2007),<sup>37</sup> research and clinical focus still tends to be based only on body structure and body function. To engage stakeholders in a trial, there needs to be explanation of why patient-reported outcomes (e.g. quality of life, participation, and subjective well-being) are important clinical outcomes.



# Acknowledgements

## Contributions of authors

**Dr Jane Goodwin** (Research Associate, Psychology) developed the survey materials, ran the survey and analysed the data; conducted and analysed the interview data; cofacilitated the focus groups and analysed the data; prepared the results from survey 1 and the interviews for publication; and contributed to writing the report and approved the final version.

**Ms Jan Lecouturier** (Senior Research Associate and Deputy Director, NIHR, Research Design Service North East and study co-applicant) was involved in the design of the study; led the qualitative research, cofacilitated the focus groups and supported the research associate with the conduct of the qualitative research and analysis of the data; and was involved in preparing the report and approved the final version.

**Dr Anna Basu** (NIHR Career Development Fellow and Honorary Consultant Paediatric Neurologist and study co-applicant) was involved in the design of the study. She commented on results from all stages of the research as they emerged. She was an author on papers published from the research. She contributed to the final report and approved the final version.

**Professor Allan Colver** (Professor of Community Child Health and study co-applicant) was involved in the design of the study. He commented on results of all stages of the research as they emerged. He was an author on papers published from the research. He contributed to the final report and approved the final version.

**Dr Sarah Crombie** (Clinical Specialist Physiotherapist and study co-applicant) was involved in the design of the study. She was involved in participant recruitment. She commented on results of all stages of the research as they emerged. She was an author on papers published from the research. She contributed to the final report and approved the final version.

**Mrs Johanna Smith** (Parent and study co-applicant) was involved in the design of the study. She was PPI lead during the project, recruiting parents to the RAG, facilitating and comoderating the RAG Facebook group and disseminating information to wider parent groups. She cofacilitated the parent focus group (Northern England). She commented on results of all stages of the research as they emerged. She was an author on papers published from the research. She drafted the *Plain English summary*, contributed to the final report and approved the final version.

**Ms Denise Howel** (Senior Lecturer in Epidemiological Statistics and study co-applicant) was involved in the design of the study. She led the quantitative research and supported the research associate with the conduct of the quantitative data analysis. She commented on results of all stages of the research as they emerged. She was an author on papers published from the research. She contributed to the final report and approved the final version.

**Professor Elaine McColl** (Professor of Health Service Research and study co-applicant) was involved in the design of the study and provided particular expertise in respect to survey methods and trial design. She commented on results of all stages of the research as they emerged. She was an author on papers published from the research. She contributed to the final report and approved the final version.

**Dr Jeremy R Parr** (Clinical Senior Lecturer/Honorary Consultant and study co-applicant) was involved in the design of the study and the analysis of results. He commented on results of all stages of the research as they emerged. He was an author on papers published from the research and approved the final version of the report.

**Dr Niina Kolehmainen** (Senior Clinical Lecturer and Honorary Consultant Allied Health Professional and study co-applicant) supported the design of the study and the analysis of results. She was an author on papers published from the research and approved the final version of the report.

**Mr Andrew Roberts** (Consultant Orthopaedic Surgeon and study co-applicant) supported the design of the study and the analysis of results. He was involved in participant recruitment. He was an author on papers published from the research and approved the final version of the report.

**Mr Keith Miller** (Rehabilitation Engineer) supported the study design and the analysis of results. He was an author on papers published from the research and approved the final version of the report.

**Dr Jill Cadwgan** (previously Kisler; Consultant Paediatrician and Associate Clinical Researcher) was lead applicant and was ultimately responsible for the conduct of the study, including design, ethics approval, analysis, and dissemination. She was the corresponding author on papers published from the research. She contributed to the final report and approved the final version.

## Dissemination

### Publications

Goodwin J, Lecouturier J, Crombie S, Smith J, Basu A, Colver A, *et al.* Understanding frames: a qualitative study of young people's experiences of using standing frames as part of postural management for cerebral palsy. *Child Care Health Dev* 2018;**44**:203–11.

Goodwin J, Colver A, Basu A, Crombie S, Howel D, Parr JR, *et al.* Understanding frames: a UK survey of parents and professionals regarding the use of standing frames for children with cerebral palsy. *Child Care Health Dev* 2018;**44**:195–202.

### Conferences

Crombie S, Goodwin J, Cadwgan J. *Understanding Frames: A UK Survey of Parents and Professionals Regarding the Use of Standing Frames for Children with Cerebral Palsy*. The Association of Paediatric Chartered Physiotherapists Conference, Cardiff, 3–4 November 2017.

Cadwgan J, Goodwin J. *Understanding Frames: Evaluating 'Inherited' Clinical Practice in Children and Young People with Cerebral Palsy*. Royal College of Paediatrics and Child Health Annual Conference, Birmingham, 24–6 May 2017.

Goodwin J, Lecouturier J, Crombie S, Smith J, Cadwgan J. *Understanding Frames: Young People's Experiences of Using Standing Frames as Postural Management in Cerebral Palsy*. European Academy of Childhood Disability Annual Meeting, Amsterdam, 17–20 May 2017.

Goodwin J, Lecouturier J, Crombie S, Smith J, Cadwgan J. *Understanding Frames: Implementation of Standing Frames as Part of Postural Management for Children with Cerebral Palsy in the Classroom*. European Academy of Childhood Disability Annual Meeting, Amsterdam, 17–20 May 2017.

Goodwin J, Colver A, Basu A, Crombie S, Howel D, Parr J, *et al.* *Understanding Frames: A UK Survey of Parents and Professionals Regarding the Use of Standing Frames for Children with Cerebral Palsy*. European Academy of Childhood Disability Annual Meeting, Amsterdam, 17–20 May 2017.

Goodwin J, Lecouturier J, Crombie S, Smith J, Cadwgan J. *Understanding Frames: Young People's Experiences of Using Standing Frames as Postural Management in Cerebral Palsy*. Great North Children's Research Community Conference, Newcastle upon Tyne, 10 March 2017.

Goodwin J, Lecouturier J, Crombie S, Smith J, Cadwgan J. *Young People's Experiences of Using Standing Frames as Postural Management in Cerebral Palsy*. Young Person's Advisory Group – North England. Young People's Voices: Shaping the Future of Research and Healthcare, Newcastle upon Tyne, 1 December 2016.

### Data-sharing statement

All data requests should be submitted to the corresponding author for consideration. Access to anonymised data may be granted following review.



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# Appendix 1 Survey 1: parents



## Survey 1 Standing frames for parents and carers

### 1. Introduction and Consent

We would like to invite you to participate in this national research study “Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?” This study is being carried out by a research team from Newcastle University and is funded by The National Institute for Health Research Health Technology Assessment (NIHR HTA) Programme.

You are invited to participate in this study because you are a parent or carer of a child with cerebral palsy who may use a standing frame.

The purpose of this research study is to understand the current use of standing frames in children with cerebral palsy in the UK. If you agree to take part in this study, you will be asked to complete the survey on the next page. This survey will ask about your experience of standing frame use, and current postural management using standing frames for children with cerebral palsy. It will take you approximately 15 minutes to complete.

You may not directly benefit from this research; however, we hope that your participation in the study may improve understanding of current practice in standing frame use in the UK, to inform future research into standing frames as part of postural management for children with cerebral palsy. Your answers in this study will remain anonymous.

You do not need to give us any contact information; however at the end of the survey we will ask if you would like to be contacted regarding further research into standing frames; if you do provide us with your contact information at this stage; this information will be separated from your survey responses and kept securely by the research team. It will not be used for any other purpose than contacting you about further research. We will not give these details to any other parties. Your participation in this study is completely voluntary and you can withdraw at any time. If you have questions about this project or if you have a research-related problem, you may contact the researcher(s).

By clicking on “I agree” to the survey/questionnaire below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study. Please print a copy of this page for your records. Please **ONLY** input your contact details on the survey/questionnaire if you agree to future contact from the research team and **ONLY** on the page indicated.

**1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey**

- ☐ I agree to continue and complete the survey.
- ☐ I do not wish to continue with the survey.

**2. About you**

**Many parents and carers may also have a professional role working with children with cerebral palsy who use standing frames.**

**2. My experience of using standing frames for children with cerebral palsy is based on my role as:**

(please tick all that apply)

- ☐ Parent/carer
- ☐ Classroom Support/Teacher
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy Assistant or Technical Instructor
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Other (please specify)

If you do have an alternative professional role working with children with cerebral palsy who use standing frames:

**Please complete this survey as a parent/carer.**

However, we would be delighted if you also access the website link at the end of the survey to complete our survey for professionals who work with children with cerebral palsy.

**3. Details of your child****3. Please tell us the age of your child****4. My child has cerebral palsy**

- ☐ Yes
- ☐ No
- ☐ I don't know

If No or I don't know, please write in the box below if they have another named diagnosis

**5. Their cerebral palsy affects**

- ☐ One side of their body only
- ☐ Both sides of their body but mainly legs rather than arms
- ☐ Their whole body

**6. My child's level of mobility (please tick all the answers that apply to your child)**

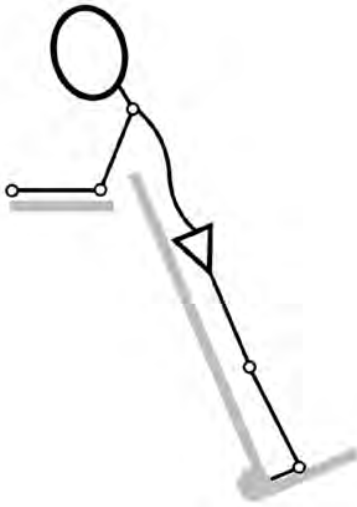
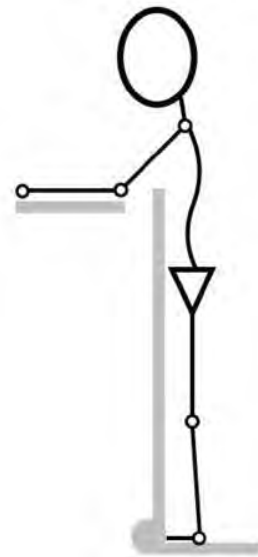
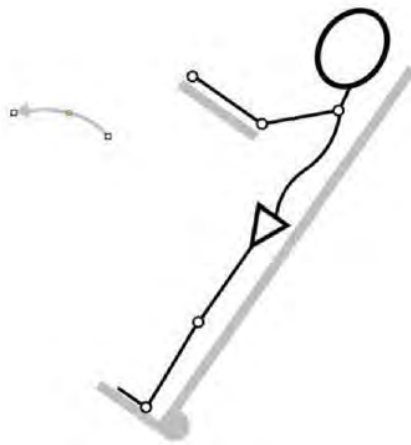
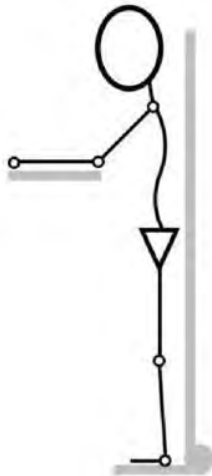
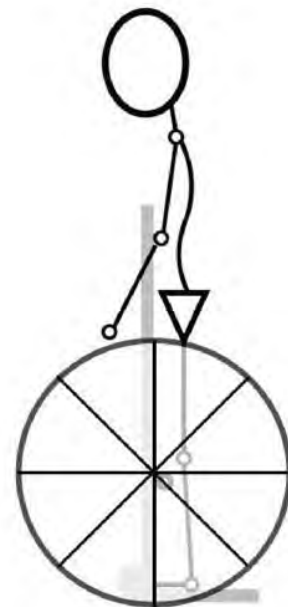
- ☐ My child can walk independently without a walking aid
- ☐ My child can walk with a walking aid (frame or stick)
- ☐ My child uses a walking aid (frame or sticks) indoors only
- ☐ My child uses a walking aid (frame or sticks) both in and outdoors
- ☐ My child uses a walking aid (frame or sticks) in therapy sessions only
- ☐ My child can sit independently
- ☐ My child can weight bear to transfer independently
- ☐ My child can weight bear to transfer with carer support
- ☐ My child needs lifting or hoisting for transfer
- ☐ My child can maintain head position in supportive seating independently
- ☐ My child is unable to maintain head position without support

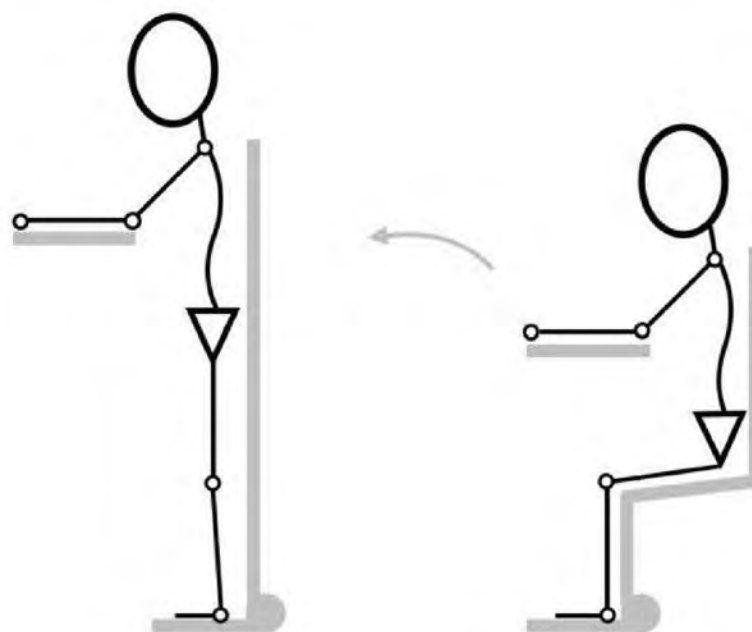
**4. Your child's standing frame use****7. Which type(s) of standing frame(s) do you and your child have experience of using?  
(Please tick all that apply)**

Please refer to the pictures below.

- ☐ Fixed prone standing frame
- ☐ Upright standing frame
- ☐ Supine standing frame
- ☐ Dynamic frame
- ☐ Sit to stand frame

If you are not sure about the type(s) of standing frame(s) you have used, you can enter a description of the frame(s) or name(s) below.

*Fixed Prone Standing Frame**Upright Standing Frame**Supine Standing Frame**Dynamic Standing Frame*

*Sit to Stand Frame*

## 5. Your child's standing frame

### 8a. How have your child's standing frame(s) been funded? (Please tick all that apply)

- ☐ Statutory services (health, social care or education)
- ☐ Charity funding
- ☐ Private or self funding
- ☐ I don't know

If you have sought charity funding or privately funded a standing frame for your child, please state why in the box below.

### 8b. Please tell us the type of school your child attends. If your child has split placement, please tick all that apply:

#### *Mainstream school*

- ☐ Local Authority (maintained) (including voluntary aided faith schools)
- ☐ Academy
- ☐ Independent or voluntary sector
- ☐ Local Authority school with additionally resourced provision (ARP) or centre (ARC)

#### *Special school*

- ☐ Local Authority school or 6<sup>th</sup> form college
- ☐ Academy
- ☐ Independent or voluntary sector

*Post 16 placement*Mainstream 6<sup>th</sup> Form

- ☐ Local Authority school or 6<sup>th</sup> form college
- ☐ Academy
- ☐ Independent or voluntary sector school or 6<sup>th</sup> form college

Special School

- ☐ Local Authority school
- ☐ Independent or voluntary sector school or 6<sup>th</sup> form college

College of Further Education

- ☐ Mainstream course of study
- ☐ Specialist curriculum (Learning Difficulties and/or Physical Disabilities)

Specialist College (independent or voluntary sector)

- ☐ Day pupil
- ☐ Residential placement

If other (e.g. EOTAS [education other than at school], PRU [pupil referral unit] etc) please specify in the box below.

|  |
|--|
|  |
|--|



6. Assessment and monitoring of your child and their standing frame use

**9. Who assessed and fitted your child's current or most recent standing frame? (Please tick all that apply)**

- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Frame Manufacturer/Representative
- ☐ Therapy Assistant
- ☐ I don't know

Other (please specify)

**10. Who has monitored your child's current or most recent standing frame? (Please tick all that apply)**

- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Frame Manufacturer/Representative
- ☐ Therapy Assistant
- ☐ I don't know

Other (please specify)

7. The current recommendation for your child regarding using a standing frame

**Not all children with cerebral palsy are prescribed a standing frame at all ages.**

**11. At what age did your child first use a standing frame?**

**12. The current recommendation for using a standing frame for your child**

- ☐ A standing frame has previously been recommended and used by my child; but is not recommended at the current time
- ☐ A standing frame is currently recommended for my child

If a standing frame has previously been recommended and used by your child; but is not recommended at the current time, please go to **QUESTION 13, SECTION 8**.

If a standing frame is currently recommended for your child, please go to **QUESTION 15, SECTION 9**.

8. Your child's experience of previously using a standing frame

**13. Please tell us the age your child stopped using a standing frame**

*We are an experienced team of clinicians and researchers and have developed this survey with parents and young people who have used standing frames.*

*We recognise that there are lots of practical reasons why using standing frames can be difficult. Please help us to understand more about your experience of using standing frames in the following questions.*

**14. Have you or your child experienced any of these recognised difficulties of using a standing frame?**

- ☐ There was sometimes not enough time for my child to use a standing frame at home
- ☐ We have had difficulties with other equipment (e.g. a hoist) to use to position our child into the standing frame
- ☐ My child sometimes wanted a rest from using a standing frame
- ☐ There were sometimes moving and handling difficulties at home for my child (e.g. safety concerns)
- ☐ There was limited space to use or store the standing from
- ☐ There were not always enough people (parents or carers) to position my child in the standing frame
- ☐ My child disliked standing in their standing frame
- ☐ My child experienced pain when standing in their standing frame

Other (please specify)

Please go to **QUESTION 24, SECTION 14**

## 9. Using standing frames at home

*We are an experienced team of clinicians and researchers and have developed this survey with parents and young people who have used standing frames.*

*We recognise that there are lots of practical reasons why using standing frames at home can be difficult. Please help us to understand more about your experience of using standing frames at home in the following questions.*

### 15. Does your child use a standing frame at home?

- ☐ Yes – and they continue to use a standing frame at home
- ☐ No – a frame is available for use at home but it is not currently being used
- ☐ No – they do not have a standing frame at home at present but they have used a standing frame at home previously
- ☐ No – they have never used a standing frame at home

If a standing frame is used at home, please go to QUESTION 13, SECTION 8.

If a standing frame is not used at home, please go to QUESTION 20, SECTION 12.

## 10. Using standing frames

### 16. Does your child use a standing frame during the school/nursery holidays?

- ☐ Yes
- ☐ No
- ☐ I don't know

If Yes, where do they use a standing frame?

### 17. Please tell us the reason(s) why your child does not use a standing frame at home currently (please tick all that apply)

- ☐ Using a standing frame at home has not been recommended for my child
- ☐ There is not enough time for my child to use a standing frame at home
- ☐ We do not have a standing frame at home
- ☐ We do not have access to equipment (e.g. a hoist) to use to position our child into the standing frame
- ☐ My child wants a rest from therapy at home or in school holidays
- ☐ There are moving and handling difficulties at home for my child (e.g. safety concerns)
- ☐ There is not enough space at home to use or store the standing frame
- ☐ There are not enough people (parents or carers) at home to position my child in the standing frame
- ☐ My child dislikes standing in a standing frame
- ☐ My child experiences pain when standing in a standing frame

Other reasons (please specify)

## 11. Your child's current standing programme

*We know that not all children are able to stand in their frames as much as it is recommended – please try to answer the following questions as honestly as possible – we need to understand how easy or difficult it is for families to use standing frames.*

### 18. Firstly we'd like to know how often your child stands in their frame

|   | At school  | At short break care or other location  |
|---|--|--|
| How often is it recommended that your child stands in their standing frame currently? | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure |
| How often does your child manage to stand in their standing frame currently?          | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure |

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it, please can you tell us the reasons why?

**19. Secondly, we'd like to know how long your child stands in their frame – each time they stand**

|  | At school  | At short break care or other location  |
|--|--|--|
| How long is it recommended that your child stands in their standing frame currently? | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> My child does not attend short break care or stay at another location<br><input type="checkbox"/> I am not sure |

|   | At school  | At short break care or other location  |
|---|--|--|
| How long does your child manage to stand in their standing frame currently? | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> My child does not attend short break care or stay at another location<br><input type="checkbox"/> I am not sure |

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it, please can you tell us the reasons why?

Please go to **QUESTION 24, SECTION 14.**

**12. Using standing frames at home****20. When does your child use their standing frame at home (please tick all that apply)**

- ☐ On weekdays outside school/nursery hours
- ☐ At weekends
- ☐ During school holidays

**21. Have you or your child experienced any of these recognised difficulties with using standing frames at home in the last 6 months? (please tick all that apply)**

- ☐ There is sometimes not enough time for my child to use a standing frame at home
- ☐ We have had difficulties with other equipment (e.g. a hoist) to use to position our child into the standing frame
- ☐ My child sometimes wants a rest from therapy at home
- ☐ There are sometimes moving and handling difficulties at home for my child (e.g. safety concerns)
- ☐ There is limited space at home to use or store the standing frame
- ☐ There are not always enough people (parents or carers) at home to position my child in the standing frame
- ☐ My child dislikes standing in their standing frames
- ☐ My child experiences pain when standing in their standing frame

Other reasons (please specify)

|  |
|--|
|  |
|--|



## 13. Your child's current standing programme

*We know that not all children are able to stand in their frames as much as it is recommended – please try to answer the following questions as honestly as possible – we need to understand how easy or difficult it is for families to use standing frames.*

## 22. Firstly we'd like to know how often your child stands in their frame

|   | At home  | At school  | At short break or other location   |
|---|--|--|--|
| How often is it recommended that your child stands in their standing frame currently? | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure |

|  | At home  | At school  | At short break or other location   |
|--|--|--|--|
| How often does your child manage to stand in their standing frame currently? | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> Every day<br><input type="checkbox"/> More than 3 times each week<br><input type="checkbox"/> More than once each week<br><input type="checkbox"/> Once each week<br><input type="checkbox"/> Less than once each week<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure |

Is there a difference between how often it is recommended that your child uses their frame and how often they manage to use it - please can you tell us the reasons why?

**23. Secondly, we'd like to know how long your child stands in their frame – each time they stand**

|   | At home  | At school  | At short break or other location   |
|---|--|--|--|
| How often is it recommended that your child stands in their standing frame currently? | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> My child does not attend short break care or stay at another location<br><input type="checkbox"/> I am not sure |

|  | At home  | At school  | At short break or other location   |
|--|--|--|--|
| How often does your child manage to stand in their standing frame currently? | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> I am not sure | <input type="checkbox"/> More than 2 hours<br><input type="checkbox"/> 1 to 2 hours<br><input type="checkbox"/> 30 minutes to 1 hour<br><input type="checkbox"/> Less than 30 minutes<br><input type="checkbox"/> Not recommended in this location<br><input type="checkbox"/> My child does not attend short break care or stay at another location<br><input type="checkbox"/> I am not sure |

Is there a difference between the time it is recommended that your child stands in their frame and how long they manage to stand – please can you tell us the reason why there is a difference?

#### 14. Benefits for children with cerebral palsy using standing frames

*There are many reported benefits of using standing frames for children with cerebral palsy. Below some of them are listed. You will see the list twice.*

*In the first question, we would be grateful if you could tick all the benefits that you may have seen. In the second question, please only tick 3 benefits that you feel have been most important to your child.*

#### **24. How do you think your child benefits or has benefited from using a standing frame? (please tick all that apply)**

- ☐ To participate in activities
- ☐ To enjoy activities
- ☐ To help my child communicate
- ☐ To be at the same level as his/her peers and to interact/play with them
- ☐ To give my child an opportunity for a change of position
- ☐ To help my child use their vision
- ☐ To improve breathing
- ☐ To improve bladder and bowel functions
- ☐ To help my child stand independently in future
- ☐ To help my child walk in future
- ☐ To improve my child's motor abilities e.g. trunk control
- ☐ To improve my child's motor abilities e.g. head control
- ☐ To improve my child's motor abilities e.g. using their hands
- ☐ To reduce risk of joint contractions (keep their legs straight as they grow)
- ☐ To reduce risk of hip dislocation or damage
- ☐ To improve my child's bone strength
- ☐ To reduce risk of fractures

Other reasons (please specify)

**25. Please indicate from the repeated list below the 3 most important benefits to your child**

- ☐ To participate in activities
- ☐ To enjoy activities
- ☐ To help my child communicate
- ☐ To be at the same level as his/her peers and to interact/play with them
- ☐ To give my child an opportunity for a change of position
- ☐ To help my child use their vision
- ☐ To improve breathing
- ☐ To improve bladder and bowel functions
- ☐ To help my child stand independently in future
- ☐ To help my child walk in future
- ☐ To improve my child's motor abilities e.g. trunk control
- ☐ To improve my child's motor abilities e.g. head control
- ☐ To improve my child's motor abilities e.g. using their hands
- ☐ To reduce risk of joint contractions (keep their legs straight as they grow)
- ☐ To reduce risk of hip dislocation or damage
- ☐ To improve my child's bone strength
- ☐ To reduce risk of fractures

Other reasons (please specify)

|  |
|--|
|  |
|--|

**26. In our experience there are often delays in starting a standing programme, or replacing equipment for children who use standing frames. Please indicate the waiting times your child has experienced below**

The shortest time that my child has waited for standing frame after it has been recommended:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember

The longest time that my child has waited for standing frame after it has been recommended:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember

**27. Please add any other comments regarding you and your child's experience of using standing frames that you have not included in the questions above**

15. Further research – invitation for parents and carers to participate in focus group discussions

*As part of this research project we will be arranging some further group discussions for parents and individual interviews for young people with cerebral palsy to give us their views about using standing frames.*

*If you would like to hear more about this further research or you and/or your child are interested in taking part – please fill in details below. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.*

**28. Please indicate below if you are a parent who would like further information to participate further in this research**

- ☐ I am a parent/carers and I would be interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects
- ☐ I am not interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects

16. Contact details for parents and carers interested in participating in focus groups

*Thank you very much for your input with the survey so far and your interest in participating further in the study.*

*We have invited a large number of parents and carers to complete the survey; and will only be inviting 15-20 parents to focus groups. Please don't be too disappointed if you're not invited.*

*Please note that by providing your contact details you are not committed to attending the focus group, we will contact you with more information and you can choose not to participate at any time, without needing to give us a reason.*

*We will, of course, keep you updated with the progress of this research and results of the survey.*

**29. Please leave your contact details below for us to contact you regarding further information on the research and participation in focus groups**

|               |                      |
|---------------|----------------------|
| Name          | <input type="text"/> |
| Address       | <input type="text"/> |
| Address 2     | <input type="text"/> |
| City/Town     | <input type="text"/> |
| Postcode      | <input type="text"/> |
| Country       | <input type="text"/> |
| Email address | <input type="text"/> |
| Phone number  | <input type="text"/> |

17. Further research – invitation for young people to attend an interview about using standing frames

*As part of this research project we will be arranging some individual interviews for young people age 8-18 years with cerebral palsy to give us their views about using standing frames.*

*If you would like to hear more about this further research or you and/or your child are interested in taking part – please fill in details below. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.*

**30. Please indicate below if you would be interested in further research and participation of your child in individual interviews to give us their views about standing frames**

- ☐ My child is 8-18 years and I am happy to provide my child's information and to be contacted with more information about interviews
- ☐ I do not wish to provide my child's information or be contacted about my child participating in interviews

16. Contact details for information regarding your child's participation in an interview

*Thank you very much for your input with the survey so far and your interest in participating further in the study.*

*We have invited a large number of parents and carers to complete the survey; and will only be inviting 15-20 parents to focus groups. Please don't be too disappointed if you're not invited. Please note that by providing your contact details you are not committed to attending the focus group, we will contact you with more information and you can choose not to participate at any time, without needing to give us a reason.*

*We will, of course, keep you updated with the progress of this research and results of the survey.*

**31. Please leave your contact details below for us to contact you regarding further information on the research and participation of your child in interviews or focus groups**

|               |                      |
|---------------|----------------------|
| Name          | <input type="text"/> |
| Address       | <input type="text"/> |
| Address 2     | <input type="text"/> |
| City/Town     | <input type="text"/> |
| Postcode      | <input type="text"/> |
| Country       | <input type="text"/> |
| Email address | <input type="text"/> |
| Phone number  | <input type="text"/> |

**32. What is your child's name?**

**33. What is your child's date of birth?**



## Appendix 2 Survey 1: prescribing clinicians



### Survey 1 Standing frames for Prescribers

#### 1. Introduction and Consent

We would like to invite you to participate in this national research study “Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?” This study is being carried out by a research team from Newcastle University and is funded by The National Institute for Health Research Health Technology Assessment (NIHR HTA) Programme.

You are invited to participate in this study because you are a professional who works with children with cerebral palsy who may use a standing frame.

The purpose of this research study is to understand the current use of standing frames in children with cerebral palsy in the UK. If you agree to take part in this study, you will be asked to complete the survey on the next page. This survey will ask about your experience of standing frame use, and current postural management using standing frames for children with cerebral palsy. It will take you approximately 15 minutes to complete.

You may not directly benefit from this research; however, we hope that your participation in the study may improve understanding of current practice in standing frame use in the UK, to inform future research into standing frames as part of postural management for children with cerebral palsy. Your answers in this study will remain anonymous.

You do not need to give us any contact information; however at the end of the survey we will ask if you would like to be contacted regarding further research into standing frames; if you do provide us with your contact information at this stage; this information will be separated from your survey responses and kept securely by the research team. It will not be used for any other purpose than contacting you about further research. We will not give these details to any other parties. Your participation in this study is completely voluntary and you can withdraw at any time. If you have questions about this project or if you have a research-related problem, you may contact the researcher(s).

By clicking on “I agree” to the survey/questionnaire below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study. Please print a copy of this page for your records. Please **ONLY** input your contact details on the survey/questionnaire if you agree to future contact from the research team and **ONLY** on the page indicated.

**1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey**

- ☐ I agree to continue and complete the survey.
- ☐ I do not wish to continue with the survey.

**2. Your role**

**2. My experience of using standing frames for children with cerebral palsy is based on my role as:**

(please tick all that apply)

- ☐ Parent/carer
- ☐ Classroom Support/Teacher
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy Assistant or Technical Instructor
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Other (please specify)

**3. My current role includes:**

- ☐ Working with children (0–18 years) who use standing frames – but not leading or prescribing or monitoring their use
- ☐ Prescribing and monitoring standing frame use for children (0–18 years)

This survey is designed for professionals who lead on prescribing and monitoring the use of standing frames for children with cerebral palsy.

There is an alternative survey for professionals who work with children with cerebral palsy who use standing frames.

**3. Experiences of standing frame use****4. For how many years have you prescribed standing frames for children with cerebral palsy?**

- ☐ Less than 2 years
- ☐ 2 – 5 years
- ☐ 6 – 10 years
- ☐ More than 10 years

**5. Please indicate your current working environments (please tick all that apply)**

- ☐ In-patient (hospital)
- ☐ Out patients (clinics)
- ☐ Community - home
- ☐ Community – school

Other (please specify)

|  |
|--|
|  |
|--|

**6. Please indicate below your employment information (please tick all that apply)**

- ☐ Employed by NHS or I am a clinical academic (university employed – but work in clinical practice)
- ☐ Employed via education or social care provider
- ☐ Work in private practice only

Other (please specify)

PLEASE NOTE:

IF YOU WORK IN BOTH PRIVATE PRACTICE AND FOR ANOTHER ORGANISATION PLEASE ANSWER THE SURVEY BELOW IN YOUR ROLE AS EMPLOYED BY THE OTHER ORGANISATION.

IF YOU WORK ONLY IN PRIVATE PRACTICE THEN CONTINUE TO ANSWER THE SURVEY IN THIS ROLE.

**4. Children using standing frames**

**7. Which groups of children with cerebral palsy do you prescribe frames? (Please tick all that apply)**

- ☐ GMFCS I
- ☐ GMFCS II
- ☐ GMFCS III
- ☐ GMFCS IV
- ☐ GMFCS V
- ☐ I am not familiar with GMFCS (Gross Motor Function Classification Score)

**8. How many children with cerebral palsy on your current case load are prescribed standing frames?**

- ☐ < 10 children
- ☐ 11 – 20 children
- ☐ 21 – 30 children
- ☐ > 30 children

**9. How many new prescriptions of standing frames for children with cerebral palsy have you completed in the last 12 months?**

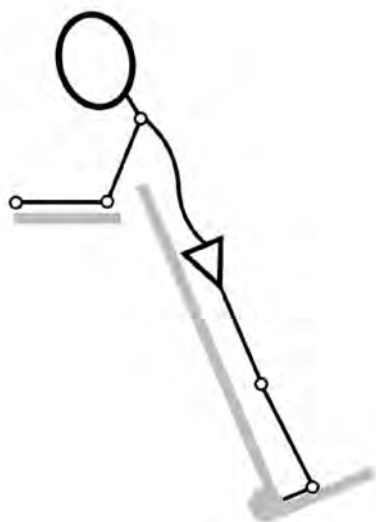
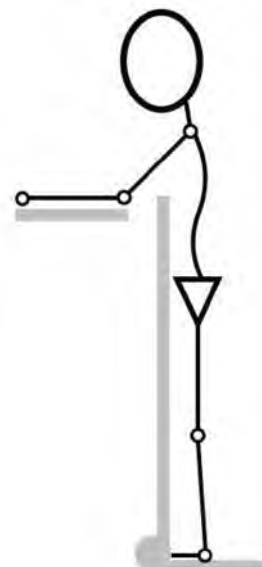
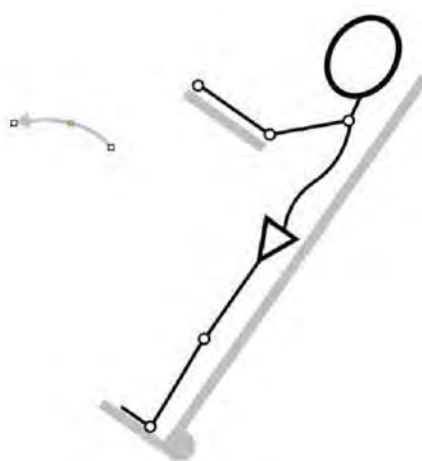
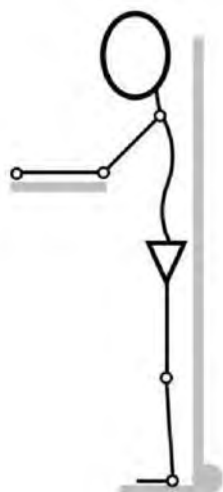
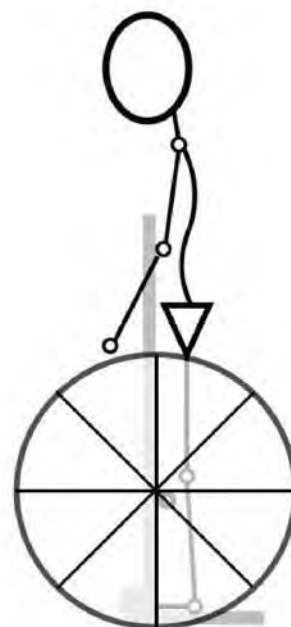
- ☐ < 10 children
- ☐ 11 – 20 children
- ☐ 21 – 30 children
- ☐ > 30 children

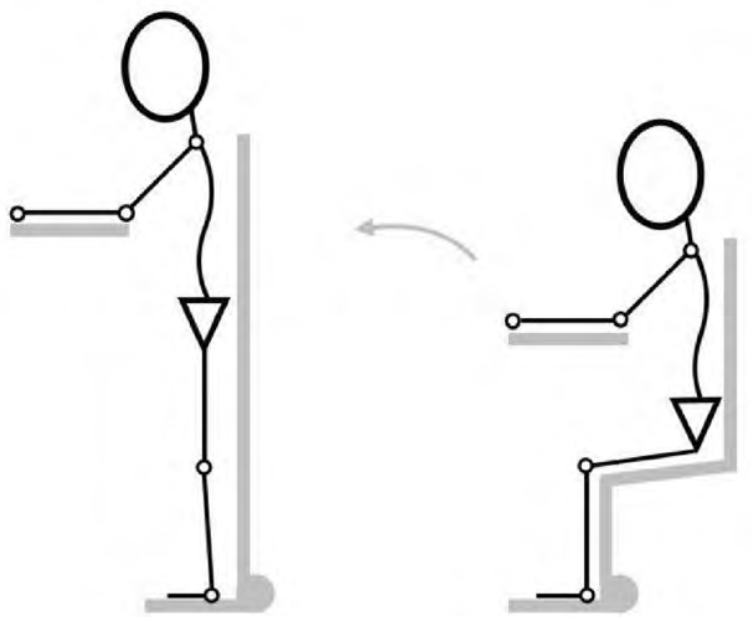
**5. Types of standing frames**

**10. Which type(s) of standing frame(s) do you have experience of using? (Please tick all that apply)**

Please refer to the pictures below.

- ☐ Fixed prone standing frame
- ☐ Upright standing frame
- ☐ Supine standing frame
- ☐ Dynamic frame
- ☐ Sit to stand frame

*Fixed Prone Standing Frame**Upright Standing Frame**Supine Standing Frame**Dynamic Standing Frame*

*Sit to Stand Frame*

## 6. Choice of standing frame

### 11. Have you experienced external factors that have influenced the choice of standing frame for children with cerebral palsy in your practice? (Please tick all that apply)

- ☐ Availability of standing frames
- ☐ Cost of standing frames or funding pathways
- ☐ Physical space
- ☐ Parent or young person choice of standing frame

Other (please specify)

## 7. Challenges to prescribed use of standing frames in children with cerebral palsy

### 12. There are some recognised challenges to standing frames prescribed use for children with cerebral palsy. Please indicate below any of these that you have experienced in your practice in the last 12 months (Please tick all that apply)

- ☐ Allocation of resources or funding for frame
- ☐ Allocation of resources for staff to prescribe/monitor use
- ☐ Physical space in home
- ☐ Availability of parents or carers at home to help position the child in the frame
- ☐ Physical space in school
- ☐ Availability of staff/carers in school to help position the child in the frame
- ☐ Transportation of equipment



Please tell us of any other challenges to standing frame prescribed use in the box below

**13. Please indicate below the current waiting times for children with cerebral palsy in your area, from identification of need (prescribers' recommendation) to commencing a programme of standing in a standing frame**

The shortest time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

Average waiting time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

Longest waiting time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

#### 8. Prescribing frames for children with cerebral palsy GMFCS IV and V

***Please note:***

***This study is to consider current UK practice and the feasibility of a trial of standing frame use in children with cerebral palsy GMFCS IV and V***

***Please answer the following questions thinking of these groups only***

**14. At what age would you first consider starting standing frame use for children with CP GMFCS IV and V?**

- ☐ Less than 6 months
- ☐ 7 – 12 months
- ☐ 13 – 18 months
- ☐ 19 – 24 months
- ☐ 25 – 30 months
- ☐ More than 30 months

What factors may influence your decision to delay starting standing frame use in children GMFCS IV or V?

**15. Please indicate the frequency that you would IDEALLY recommend that children with cerebral palsy GMFCS IV or V stands in their standing frame?**

- ☐ Every day
- ☐ More than three times each week
- ☐ More than once each week
- ☐ Once each week
- ☐ Less than once each week

Other (please specify)

**9. Standing programme for children with cerebral palsy GMFCS IV and V**

**16. Please indicate the IDEALLY recommended duration of standing, each time a child with cerebral palsy GMFCS IV or V stands in their frame?**

- ☐ More than 120 minutes (2 hours)
- ☐ 91 minutes to 120 minutes (2 hours)
- ☐ 61 minutes to 90 minutes
- ☐ 31 minutes to 60 minutes (1 hour)
- ☐ Less than 30 minutes

**17. What influences the standing programme care pathway for children with cerebral palsy GMFCS IV and V in your area? (Please tick all that apply)**

- ☐ Individual practice of practitioners
- ☐ Written local (trust or employer) guidelines
- ☐ Written regional guidelines

If you use local or regional guidelines we would value your sharing of these guidelines.  
Please provide contact information

#### 10. Monitoring standing frame use in children with GMFCS IV and V

#### 18. For a child with CP GMFCS IV or V in whom you have prescribed a standing frame:

|  | In an ideal world   | In current practice (i.e. what is achievable?)  |
|--|---|---|
| How often would you or one of your team routinely monitor the suitability of this equipment for the child? | <input type="checkbox"/> More than once a week<br><input type="checkbox"/> Weekly<br><input type="checkbox"/> Fortnightly<br><input type="checkbox"/> Monthly<br><input type="checkbox"/> Every 3 months (or termly)<br><input type="checkbox"/> Less frequently than termly<br><input type="checkbox"/> When requested | <input type="checkbox"/> More than once a week<br><input type="checkbox"/> Weekly<br><input type="checkbox"/> Fortnightly<br><input type="checkbox"/> Monthly<br><input type="checkbox"/> Every 3 months (or termly)<br><input type="checkbox"/> Less frequently than termly<br><input type="checkbox"/> When requested |
| How often would you or one of your team review the standing programme for the child?                       | <input type="checkbox"/> More than once a week<br><input type="checkbox"/> Weekly<br><input type="checkbox"/> Fortnightly<br><input type="checkbox"/> Monthly<br><input type="checkbox"/> Every 3 months (or termly)<br><input type="checkbox"/> Less frequently than termly<br><input type="checkbox"/> When requested | <input type="checkbox"/> More than once a week<br><input type="checkbox"/> Weekly<br><input type="checkbox"/> Fortnightly<br><input type="checkbox"/> Monthly<br><input type="checkbox"/> Every 3 months (or termly)<br><input type="checkbox"/> Less frequently than termly<br><input type="checkbox"/> When requested |

Other (please specify)

**19. If it is not always you who reviews the suitability of the standing frame for the child or changes the prescription of the standing programme, please tell us the role/title of the person who would do this**

### 11. Indications for standing frames in children with cerebral palsy GMFCS IV and GMFCS V

*There are many different stated indications of standing frame use in children with cerebral palsy GMFCS IV and V at different ages.*

**20. Please consider below the indications for standing frame use in children with cerebral palsy GMFCS IV and V at different ages; and indicate in which group the indications are relevant at different ages**

|   | Less than 5 years old   | 5-11 years old  | 12 years and above  |
|---|---|---|---|
| To improve bone density/strength            | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |
| To reduce risk of fractures                 | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |
| To reduce risk of join contractures         | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |
| To reduce risk of hip dislocation or damage | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |

To participate in activities

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To enjoy activities

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve breathing

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve bladder and bowel functions

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To help the child stand independently in future

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To help them walk in future

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor abilities e.g. targeted training or trunk control

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor abilities e.g. head control

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor abilities e.g. use of upper limbs/hand function

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To give the child an opportunity for a change of position

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support communication

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support vision

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support peer interaction

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

Are there any definite contradictions to standing frame use in children with cerebral palsy GMFCS IV and V? If so please write below.

**21. Please add any other comments on standing frame use for children with cerebral palsy in the space below**

**12. Further research – invitation for prescribers to participate in focus group discussions**

*As part of this research project we will be arranging some further group discussions for professionals prescribing standing frames for children with cerebral palsy to give us their views about using standing frames and future research into standing frame use.*

*We will also be completing a further survey in 2017 to consider potential trial designs of standing frames for children with cerebral palsy.*

*If you would like to hear more about this further research or are interested in taking part – please fill in details on the next pages. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.*

**22. Please indicate below if you would like further information regarding participation in focus groups to contribute further in this research**

- ☐ I would be interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects
- ☐ I am not interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy



**13. Contact details for participants interested in participating in focus groups – 2016**

*Thank you for your interest and providing us with your contact details. We will keep you updated with the progress of the study.*

*Please note that there will be limited numbers of people who can be invited to the focus groups, and we will be inviting people with a variety of experience.*

**23. Please leave your contact details below for us to contact you regarding further information on the research and participation in focus groups**

|               |                      |
|---------------|----------------------|
| Name          | <input type="text"/> |
| Address       | <input type="text"/> |
| Address 2     | <input type="text"/> |
| City/Town     | <input type="text"/> |
| Postcode      | <input type="text"/> |
| Country       | <input type="text"/> |
| Email address | <input type="text"/> |
| Phone number  | <input type="text"/> |



## Appendix 3 Survey 1: non-prescribing professionals



### Survey 1 Standing frames Survey for Professionals

#### 1. Introduction and Consent

We would like to invite you to participate in this national research study “Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?” This study is being carried out by a research team from Newcastle University and is funded by The National Institute for Health Research Health Technology Assessment (NIHR HTA) Programme.

You are invited to participate in this study because you are a professional who works with children with cerebral palsy who may use a standing frame.

The purpose of this research study is to understand the current use of standing frames in children with cerebral palsy in the UK. If you agree to take part in this study, you will be asked to complete the survey on the next page. This survey will ask about your experience of standing frame use, and current postural management using standing frames for children with cerebral palsy. It will take you approximately 15 minutes to complete.

You may not directly benefit from this research; however, we hope that your participation in the study may improve understanding of current practice in standing frame use in the UK, to inform future research into standing frames as part of postural management for children with cerebral palsy. Your answers in this study will remain anonymous.

You do not need to give us any contact information; however at the end of the survey we will ask if you would like to be contacted regarding further research into standing frames; if you do provide us with your contact information at this stage; this information will be separated from your survey responses and kept securely by the research team. It will not be used for any other purpose than contacting you about further research. We will not give these details to any other parties. Your participation in this study is completely voluntary and you can withdraw at any time. If you have questions about this project or if you have a research-related problem, you may contact the researcher(s).

By clicking on “I agree” to the survey/questionnaire below you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study. Please print a copy of this page for your records. Please **ONLY** input your contact details on the survey/questionnaire if you agree to future contact from the research team and **ONLY** on the page indicated.

**1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey**

- ☐ I agree to continue and complete the survey.
- ☐ I do not wish to continue with the survey.

**2. Your role**

**2. My experience of using standing frames for children with cerebral palsy is based on my role as:**

(please tick all that apply)

- ☐ Parent/carer
- ☐ Classroom Support/Teacher
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy Assistant or Technical Instructor
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Other (please specify)

**3. My current role includes:**

- ☐ Working with children (0–18 years) who use standing frames – but not leading or prescribing or monitoring their use
- ☐ Prescribing and monitoring standing frame use for children (0–18 years)

This survey is designed for professionals who work with children with cerebral palsy who use standing frames.

There is an alternative survey for professionals who lead on prescribing and monitoring the use of standing frames for children with cerebral palsy.

### 3. Experiences of standing frame use

#### 4. For how many years have you worked with children who use standing frames?

- ☐ Less than 2 years
- ☐ 2 – 5 years
- ☐ 6 – 10 years
- ☐ More than 10 years

#### 5. Please indicate your current working environments (please tick all that apply)

- ☐ In-patient (hospital)
- ☐ Out patients (clinics)
- ☐ Community - home
- ☐ Community – school

Other (please specify)

|  |
|--|
|  |
|--|

#### 6. Please indicate below your employment information (please tick all that apply)

- ☐ Employed by NHS or I am a clinical academic (university employed – but work in clinical practice)
- ☐ Employed via education or social care provider
- ☐ Work in private practice only

Other (please specify)

|  |
|--|
|  |
|--|

PLEASE NOTE:

IF YOU WORK IN BOTH PRIVATE PRACTICE AND FOR ANOTHER ORGANISATION PLEASE ANSWER THE SURVEY BELOW IN YOUR ROLE AS EMPLOYED BY THE OTHER ORGANISATION.

IF YOU WORK ONLY IN PRIVATE PRACTICE THEN CONTINUE TO ANSWER THE SURVEY IN THIS ROLE.

#### 4. Children using standing frames

**7. Which groups of children with cerebral palsy do you see use standing frames? (Please tick all that apply)**

- ☐ GMFCS I
- ☐ GMFCS II
- ☐ GMFCS III
- ☐ GMFCS IV
- ☐ GMFCS V
- ☐ I am not familiar with GMFCS (Gross Motor Function Classification Score)

**8. How many children with cerebral palsy on your current case load are prescribed standing frames?**

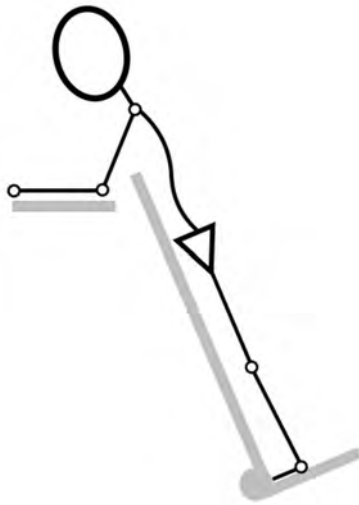
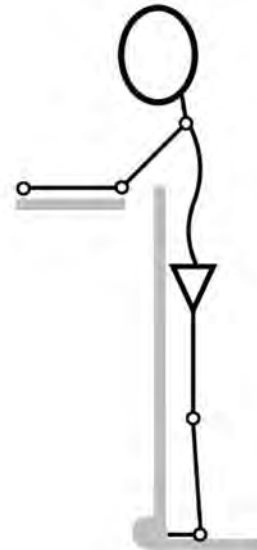
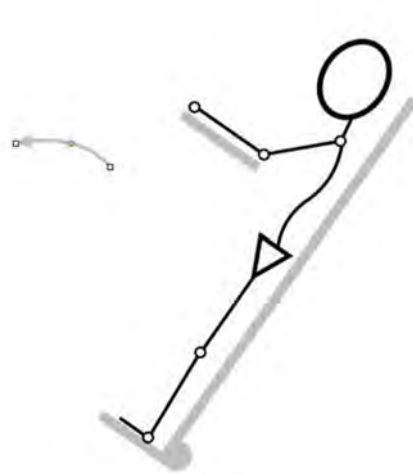
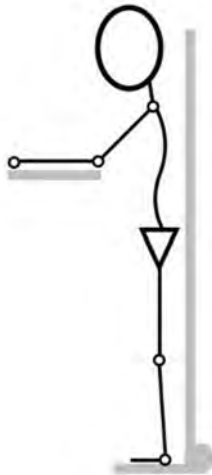
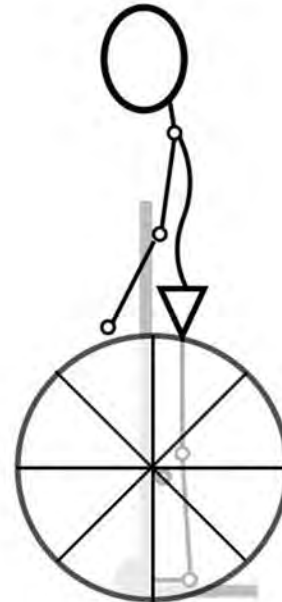
- ☐ < 10 children
- ☐ 11 – 20 children
- ☐ 21 – 30 children
- ☐ > 30 children

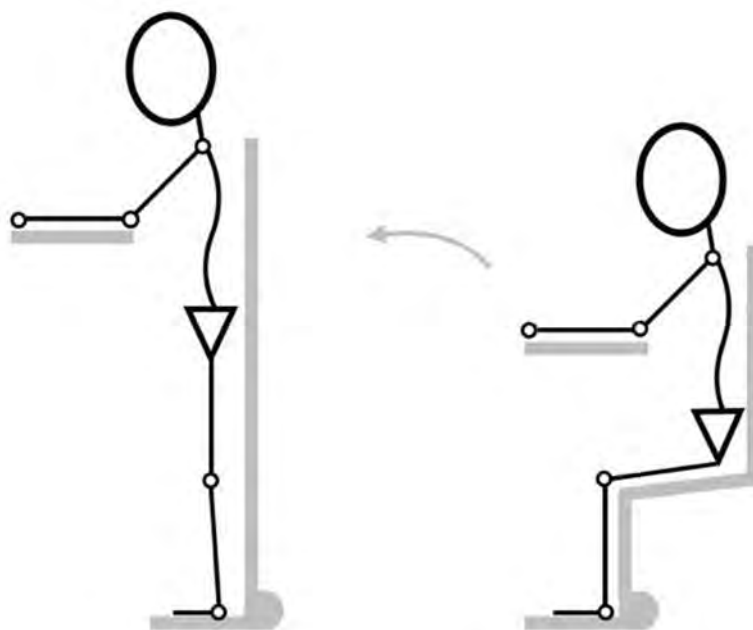
#### 5. Types of standing frames

**9. Which type(s) of standing frame(s) do you have experience of using? (Please tick all that apply)**

Please refer to the pictures below.

- ☐ Fixed prone standing frame
- ☐ Upright standing frame
- ☐ Supine standing frame
- ☐ Dynamic frame
- ☐ Sit to stand frame

***Fixed Prone Standing Frame******Upright Standing Frame******Supine Standing Frame******Dynamic Standing Frame***

*Sit to Stand Frame*



## 6. Standing frame use

### 10. Have you experienced external factors that have influenced the choice of standing frame for children with cerebral palsy in your practice? (Please tick all that apply)

- ☐ Availability of standing frames
- ☐ Cost of standing frames or funding pathways
- ☐ Physical space
- ☐ Parent or young person choice of standing frame

Other (please specify)

## 7. Challenges to prescribed use of standing frames in children with cerebral palsy

### 11. There are some recognised challenges to standing frames prescribed use for children with cerebral palsy. Please indicate below any of these that you have experienced in your practice in the last 12 months (Please tick all that apply)

- ☐ Allocation of resources or funding for frame
- ☐ Allocation of resources for staff to prescribe/monitor use
- ☐ Physical space in home
- ☐ Availability of parents or carers at home to help position the child in the frame
- ☐ Physical space in school
- ☐ Availability of staff/carers in school to help position the child in the frame
- ☐ Transportation of equipment

Please tell us of any other challenges to standing frame prescribed use in the box below

**12. Please indicate below the current waiting times for children with cerebral palsy in your area, from identification of need (prescribers recommendation) to commencing a programme of standing in a standing frame**

The shortest time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

Average waiting time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

Longest waiting time for standing frame programme in last year:

- ☐ Less than 4 weeks
- ☐ 4 – 8 weeks
- ☐ 9 – 13 weeks
- ☐ 14 – 20 weeks
- ☐ 21 – 25 weeks
- ☐ More than 26 weeks
- ☐ I don't remember
- ☐ I don't know

#### 8. Prescribing frames for children with cerebral palsy GMFCS IV and V

***Please note:***

***This study is to consider current UK practice and the feasibility of a trial of standing frame use in children with cerebral palsy GMFCS IV and V***

***Please answer the following questions thinking of these groups only***

#### **13. At what age would you first consider starting standing frame use for children with CP GMFCS IV and V?**

- ☐ Less than 6 months
- ☐ 7 – 12 months
- ☐ 13 – 18 months
- ☐ 19 – 24 months
- ☐ 25 – 30 months
- ☐ More than 30 months
- ☐ I don't know – I would rely on the prescriber to advise

What factors may influence your decision to delay starting standing frame use in children GMFCS IV or V?

**14. Please indicate the frequency that you would IDEALLY recommend that children with cerebral palsy GMFCS IV or V stands in their standing frame?**

- ☐ Every day
- ☐ More than three times each week
- ☐ More than once each week
- ☐ Once each week
- ☐ Less than once each week
- ☐ I don't know – I would rely on the prescriber to advise
- Other (please specify)

**15. Please indicate the IDEALLY recommended duration of standing, each time a child with cerebral palsy GMFCS IV and V stands in their frame?**

- ☐ More than 120 minutes (2 hours)
- ☐ 91 – 120 minutes (2 hours)
- ☐ 61 – 90 minutes
- ☐ 31 – 60 minutes (1 hour)
- ☐ Less than 30 minutes
- ☐ I don't know – I would rely on the prescriber to advise

**16. What influences the standing programme care pathway for children with cerebral palsy GMFCS IV or V in your area? (Please tick all that apply)**

- ☐ Individual practice of practitioners
- ☐ Written local (trust or employer) guidelines
- ☐ Written regional guidelines

If you use local or regional guidelines we would value your sharing of these guidelines.  
Please provide contact information

**9. Indications for standing frames in children with cerebral palsy GMFCS IV and GMFCS V**

*There are many different stated indications of standing frame use in children with cerebral palsy GMFCS IV and V at different ages.*

**17. Please consider below the indications for standing frame use in children with cerebral palsy GMFCS IV and V at different ages; and indicate in which group the indications are relevant at different ages**

|                                      | Less than 5 years old   | 5-11 years old  | 12 years and above  |
|--------------------------------------|---|---|---|
| To improve bone density/strength     | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |
| To reduce risk of fractures          | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |
| To reduce risk of joint contractures | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure | <input type="checkbox"/> GMFCS IV only<br><input type="checkbox"/> GMFCS V only<br><input type="checkbox"/> GMFCS IV and V<br><input type="checkbox"/> Never/not indicated<br><input type="checkbox"/> I don't know/I am not sure |

To reduce risk of hip  
dislocation or damage

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To participate in  
activities

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To enjoy activities

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve breathing

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve bladder and  
bowel functions

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To help the child stand  
independently in future

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To help them walk in  
future

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor  
abilities e.g. targeted  
training or trunk control

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor abilities e.g. head control

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve motor abilities e.g. use of upper limbs/hand function

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To give the child an opportunity for a change of position

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support communication

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support vision

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

To improve or support peer interaction

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

- ☐ GMFCS IV only
- ☐ GMFCS V only
- ☐ GMFCS IV and V
- ☐ Never/not indicated
- ☐ I don't know/I am not sure

Are there any definite contradictions to standing frame use in children with cerebral palsy GMFCS IV and V? If so please write below.

**18. Please add any other comments on standing frame use for children with cerebral palsy in the space below**

**10. Further research – invitation for professionals to participate in focus group discussions**

*As part of this research project we will be arranging some further group discussions for professionals who use standing frames for children with cerebral palsy to give us their views about using standing frames and future research into standing frame use.*

*We will also be completing a further survey in 2017 to consider potential trial designs of standing frames for children with cerebral palsy.*

*If you would like to hear more about this further research or are interested in taking part – please fill in details on the next pages. Please note your contact details will be stored securely (according to Trust and University regulatory guidance) and will not be shared with any other parties.*

**19. Please indicate below if you would like further information regarding participation in focus groups to contribute further in this research**

- ☐ I would be interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy and potential future research projects
- ☐ I am not interested in participating in focus group discussions regarding the use of standing frames for young people with cerebral palsy

**11. Contact details for participants interested in participating in focus groups – 2016**

*Thank you for your interest and providing us with your contact details. We will keep you updated with the progress of the study.*

*Please note that there will be limited numbers of people who can be invited to the focus groups, and we will be inviting people with a variety of experience.*



**20. Please leave your contact details below for us to contact you regarding further information on the research and participation in focus groups**

|               |                      |
|---------------|----------------------|
| Name          | <input type="text"/> |
| Address       | <input type="text"/> |
| Address 2     | <input type="text"/> |
| City/Town     | <input type="text"/> |
| Postcode      | <input type="text"/> |
| Country       | <input type="text"/> |
| Email address | <input type="text"/> |
| Phone number  | <input type="text"/> |



# Appendix 4 Single stakeholder focus groups: topic guide



## Standing frame Focus group schedule

*Note: The focus group schedule is developmental. The questions will need to be tailored to the discussion in the focus group and their level of experience/expertise. The schedule given here is therefore a general topic guide.*

### Plan of interview

1. Introductions and setting the scene.
2. Consent
3. Participants experience of using a standing frame
4. Awareness of research into medical interventions in cerebral palsy
5. What we have found out about standing frame use in the for other young people with cerebral palsy from the survey
6. What questions do you have about using standing frames and how they help young people with cerebral palsy?
7. Designing a research study into standing frame use in children with cerebral palsy
8. Feedback

### *Setting*

- *Location determined by practicalities of bringing participants together (e.g. hospital, school, meeting room)*

### Introduction

- Thank-you for attending.
- Introductions of everyone involved in group: RA, other research team members and their roles.
- Introductions of participants – acknowledge that some participants may know each other in a personal or professional role. If this is the case – re-inforce confidentiality issues and clarify that they are comfortable with continued participation.
- Explain purpose of project and this focus group:
  - We are looking for feedback from all user of standing frames: professionals, parent carers in focus groups and young people in interviews. We want to know about their experiences of using standing frames, the practicalities – good and bad.
  - No right or wrong answers – not a test of knowledge

- Ground rules of group.
- Consent – written – because we want to be reviewing content and analysing data.
- Explain group discussion recorded both with audio– to make sure that it is recorded accurately but details will be confidential
- The RA is not a clinician, but the wider research team includes doctors and therapists who do look after patients with cerebral palsy. If participants have any questions about care of a relative or client the RA can try to direct the questions to someone who can help, but would it be helpful if we use the focus group to try to find out more about your questions and opinions, so please leave any questions until the end.
- Questions or concerns?

Ask participants to read and sign consent forms.

Participants experience of using a standing frame

- Do you use a standing frame?
  - Where and when – setting of use ? School or home or other
  - How long have you been using frames
  - How many young people have you used frames with?
  - Who prescribes frames
  - What are the good things about using a standing frame – for the children/young people? What do you enjoy ?
  - What are the challenges to use? What do you not like?
- Why do you think children with cerebral palsy use standing frames?
- What other input do young people have with respect to their movement and position at home, school – daytime and night time?
  - Equipment e.g. special chairs, sleep system,
  - People e.g. physio, OT, teachers parents
  - Activities – therapy, sport, leisure

Awareness of research into interventions in cerebral palsy

RA to explain concepts of treatments and how research is designed to develop evidence

Reasons why evidence is limited

Pictures can help with explanations

General aspects of how we go about research – at a level according to the audience experience/profession.

What we have found out about standing frame use in the for other young people with cerebral palsy from the survey

Brief discussion of survey results – discuss variations in practice:

Age of starting

Duration of standing

Environment used – school, home, both, other

Practical barriers to use of frames

What questions do you have about using standing frames and how they help young people with cerebral palsy?

Are you surprised by any of the information above from the survey?

If so – what is surprising?

Designing a research study into standing frame use in children with cerebral palsy

If you were going to design a research study to investigate standing frames – what would it be about – and what would it be?

If there was a research trial in which you were allocated by chance to a different standing frame of treatment programme – would you be interested in recruiting?

What would be the barriers to recruitment?

RA will prompt with examples if needed.

RA will present 2 or 3 study design ideas to generate discussion.

Feedback

- Thank you
- Are we asking the right questions?
- Do these questions relate to your own experience?
- Do these questions allow you to talk about what is important for you?
- Is there anything else you think it would be useful for us to know?



## Appendix 5 Single stakeholder focus groups: PowerPoint presentation

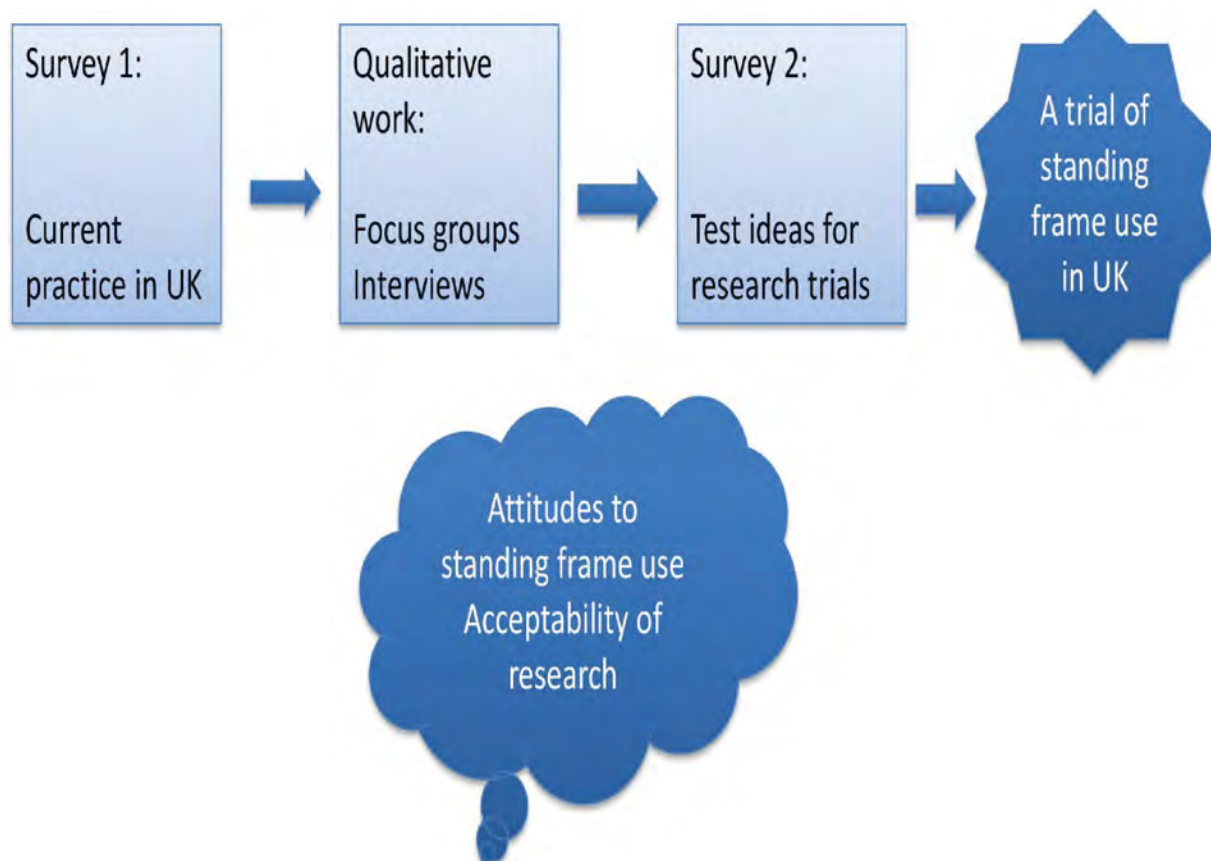


*Standing Frames as part of  
postural management for  
children with Spasticity.  
What is the acceptability of a  
trial to determine the  
efficacy of standing frames?*



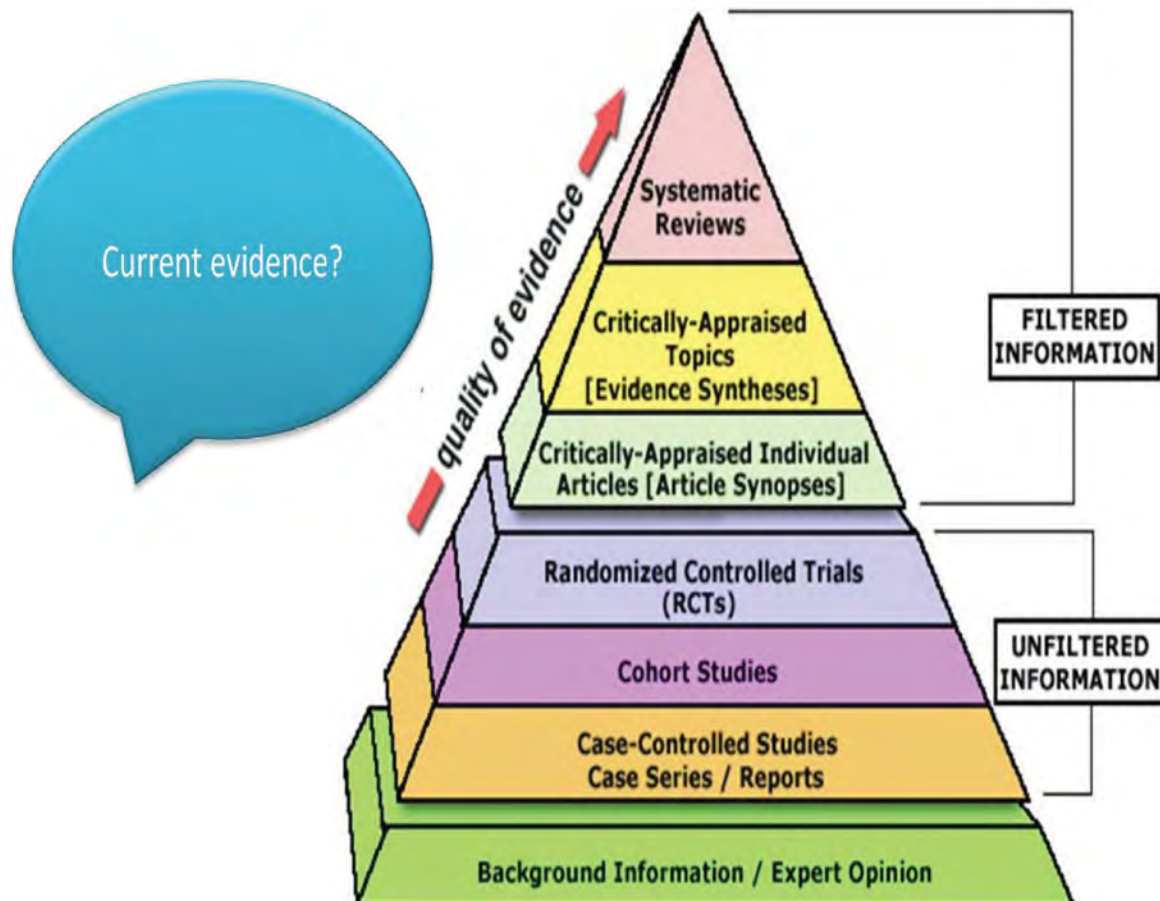
*Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.*

# understanding frames





# understanding frames



# understanding frames

Survey 1:

Current  
practice in  
UK.

UK wide  
survey:  
Professionals  
155  
Prescribers 305  
Parents 91

Limited evidence  
but significant  
consistency in  
prescribing  
practice and  
recommendations

Achieving use as  
recommended is  
not usually  
possible:  
challenges to  
use!

Widely reported  
benefits of use:  
Which are most  
important to  
whom?





## Experienced challenges of standing frame use

| Resources   | Environment  | Child factors                    |
|---|--|----------------------------------|
| Allocation of resources/funding for frame                           | Physical space in home   | Child dislikes standing in frame |
| Allocation of resources for staff to prescribe/monitor use          | Physical space at school   | Child sometimes wants a rest     |
| Time  | Transportation of equipment                                      | Child experiences pain           |
| No standing frame at home   | Moving & handling difficulties                                   |                                  |
| Standing frame not recommended for child                            | Difficulty with/access to other equipment used to position child |                                  |
| Availability of parents/carers to help position the child           |  |                                  |
| Availability of parents/carers in school to help position the child |  |                                  |





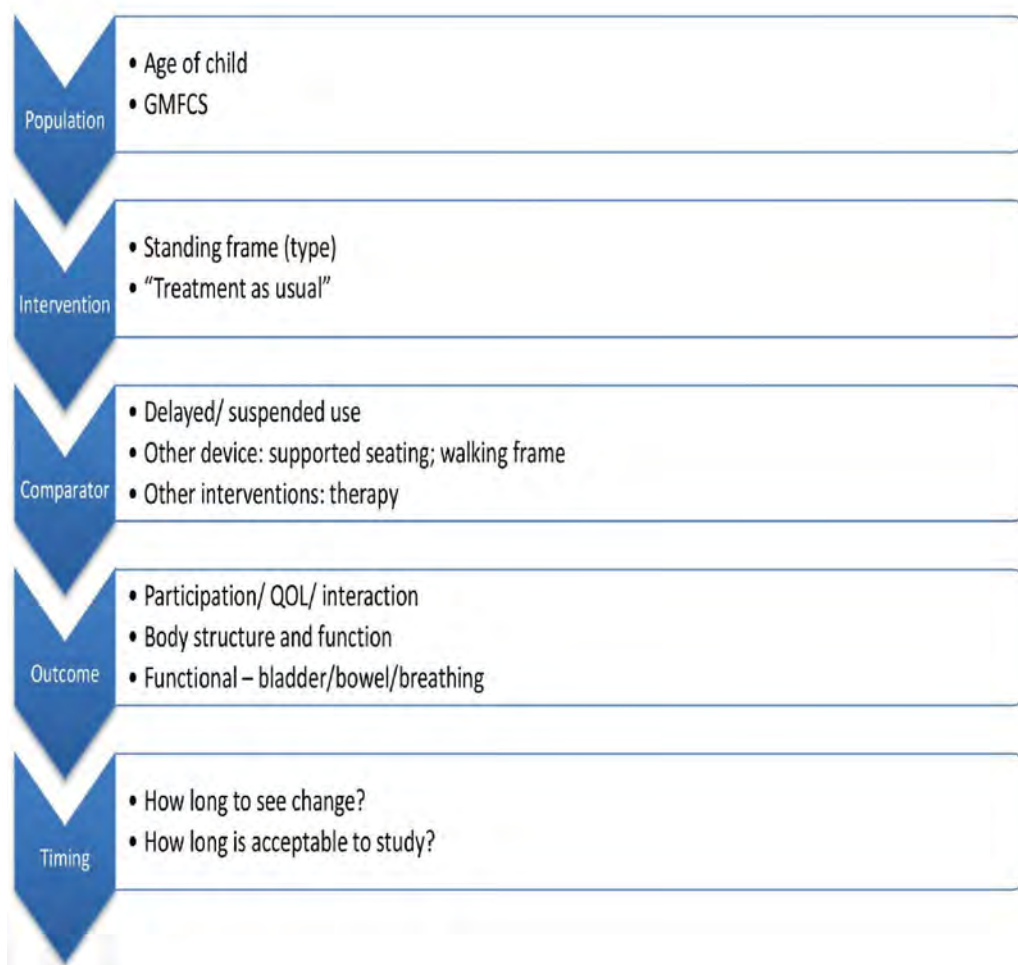
# understanding frames

## Reported benefits of standing frame use

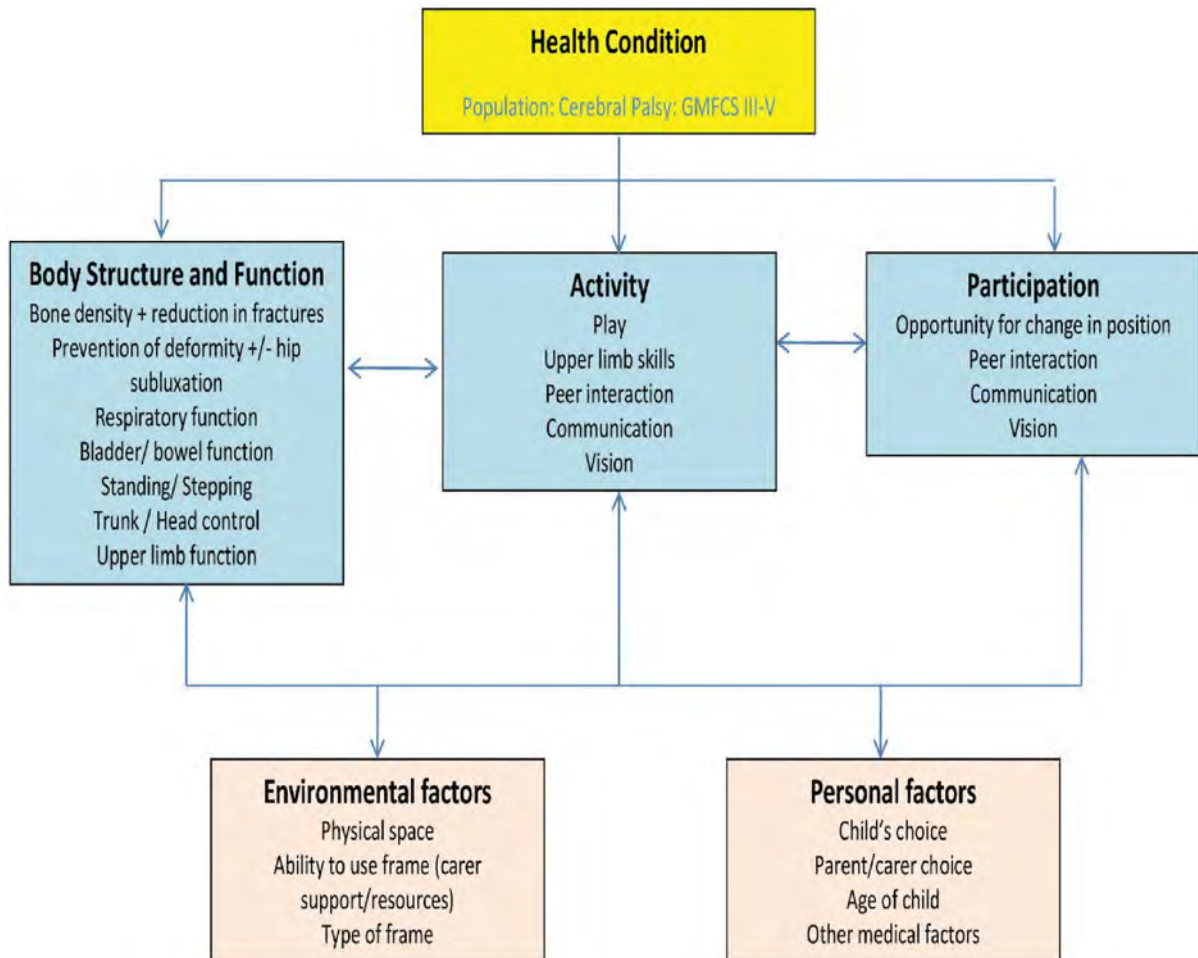
|  |                                       |   |
|--|---------------------------------------|---|
| Opportunity for change of position     | Bone strength                         | Bladder and bowel functions             |
| Reduce risk of joint contractions      | Participate in activities             | Reduce risk of hip dislocation/damage   |
| Improve motor abilities (head control) | Improve motor abilities (using hands) | Improve motor abilities (trunk control) |
| Same level as peers (play/interaction) | Enjoy activities                      | Stand independently in future           |
| Improve breathing                      | Reduce risk of fractures              | Use vision                              |
| Walk in future                         | Communicate                           | Other                                   |



# understanding frames



# understanding frames

# Appendix 6 Interviews: topic guide



## Standing frame young person's interview schedule

*Note: The interview schedule is developmental. The questions will need to be tailored to the specific answers of each interviewee. The interview schedule given here is therefore a general topic guide for the one-to-one qualitative interviews.*

### Plan of interview

1. Introduction
2. Consent
3. The young person – their use of a standing frame
4. Awareness of research into medical interventions (in cerebral palsy) be aware – check if child knows diagnosis/ understands CP
5. What we have found out about standing frame use in the for other young people with cerebral palsy from the survey
6. What questions do you have about using standing frames and how they help young people?
7. Designing a research study into standing frame use in children?
8. Feedback

### Setting

- *Location of interviewee's choice – home/school/ usual clinical environment*
- *Carer/ communication support worker as chosen by young person.*
- *Lone working policy to be followed by RA*

### Introduction

- Introductions of everyone involved in interview; RA, young person, communication support and parent/carer if present.
- Explain purpose of project and this interview:
  - Won't affect care – separate from medical care
  - We're looking for feedback from young people about their experiences of using standing frames
  - No right or wrong answers – not a test of your knowledge



- Consent – written, because this is extra to standard care.
- Explain interview recorded both with audio and video – to make sure that it is recorded accurately but details will be confidential
- The RA is not a clinician, but the wider research team includes doctors and therapists who do look after patients with cerebral palsy. If have any questions about your condition they will try to answer them at a later date or point you in the direction of someone who can help. It would be helpful if we use the interview to try to find out more about your questions, rather than spend time answering them – could we leave those questions until the end.
- Questions or concerns?

2) Consent and assent form signed and checked.

The young person – their diagnosis of cerebral palsy and use of a standing frame

- Tell us your story
- When people ask you about cerebral palsy (\* check child knows/ understands with parent/carers before), how do you explain how this/your condition affects you? Do you use a standing frame?
  - When and where do you use the frame? School or home or both
  - When did you first start using a standing frame?
  - What activities do you use it for? Who decides when it is used and what you do when you are using it?
  - Whose idea was it? Yours? Your parents? A doctor? A physio or other therapist?
  - What are the good things about using a standing frame? What do you enjoy?
  - What are the bad things? What do you not like?
  - what makes it easier or harder to use a standing frame – either external things (e.g. uneven surfaces) or internal things (e.g. they feel it is a lot of hassle)
- why do you think using a standing frame is good for you or just why they think they are using a standing frame? Do you it's helping and if so, in what way? What don't you like about using one
- What other input do you have with respect to your movement and position at home, school – daytime and night time?
  - Equipment e.g. special chairs, sleep system,
  - People e.g. physio, OT, teachers parents
  - Activities – therapy, sport, leisure



Awareness of research into interventions in cerebral palsy

RA to explain concepts of treatments and how research is designed to develop evidence

Reasons why evidence is limited

Pictures can help with explanations

General aspects of how we go about research – at a level according to the young person's developmental/ cognitive level.

What we have found out about standing frame use in the for other young people from the survey

Brief discussion of survey results – discuss variations in practice:

Age of starting

Duration of standing

Environment used – school, home, both, other

What questions do you have about using standing frames and how they help young people?

Are you surprised by any of the information above from the survey?

If so – what is surprising?

Designing a research study into standing frame use in children?

If you were going to check how well standing frame's work, what would be most important for you to know?

If there was a research trial in which you were allocated by chance to a different standing frame of treatment programme – would you be interested in participating?

RA will prompt with examples

Feedback

- Thank you
- Are we asking the right questions?
- Do these questions relate to your own experience?
- Do these questions allow you to talk about what is important for you?
- Is there anything else you think it would be useful for us to know?



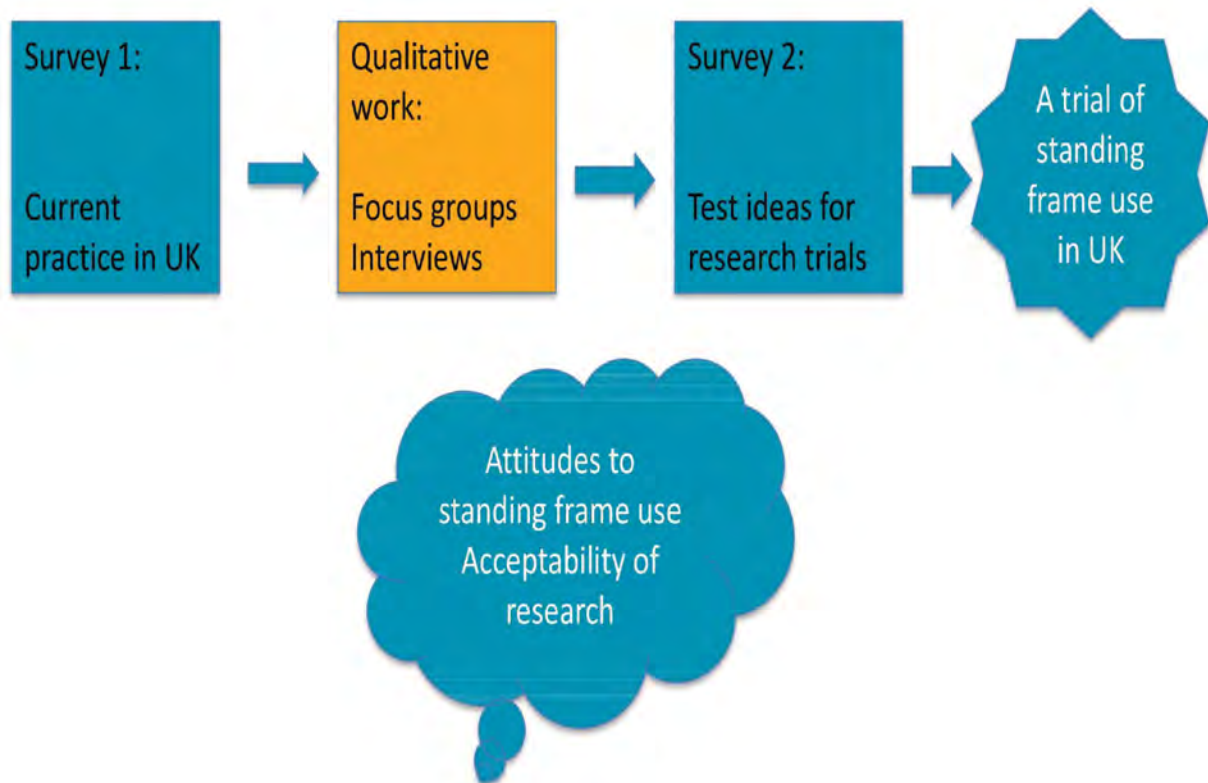
## Appendix 7 Multistakeholder focus groups: PowerPoint presentation with topic guide included



*Standing Frames as part of  
postural management for  
children with Spasticity.  
What is the acceptability of a  
trial to determine the  
efficacy of standing frames?*

*Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.*

# understanding frames



# understanding frames



Survey 1:

Current  
practice in  
UK.

UK wide  
survey:  
Professionals 155  
Prescribers 305  
Parents 91

Limited evidence  
but significant  
consistency in  
prescribing  
practice and  
recommendations

Achieving use as  
recommended is  
not usually  
possible:  
challenges to  
use!

Widely reported  
benefits of use:  
Which are most  
important to  
whom?







# understanding frames

Focus groups  
and  
Interviews:

Measuring  
outcomes of body  
structure will need  
large numbers of  
children; and long  
term follow up

Body function, activity  
and participation may  
be measured in shorter  
time frames; with a  
variety of different  
outcome measures.

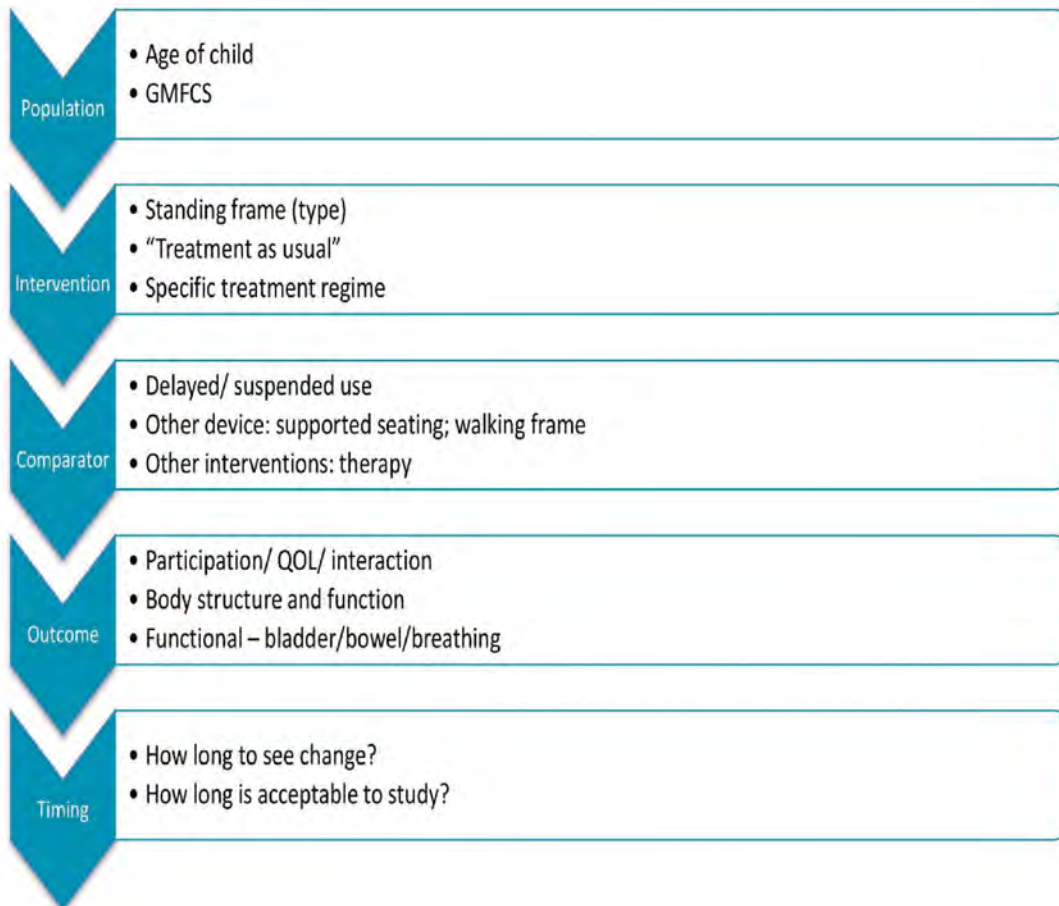
Each individual child  
and prescriber have  
goals for why they  
use frames – these  
may not always be  
the same goals.

Children are most  
focused on activity and  
participation; but do  
have opinions and belief  
that frames will be  
“good for their body  
structure” in the future

Variable practical  
issues with using  
frames in different  
environments (school  
and home)



# understanding frames



# understanding frames



Parents' reported benefits of standing frame use:



|     |  |
|-----|--|
| 1   | Opportunity for a change of position     |
| 2   | Reduce risk of hip dislocation or damage |
| = 3 | Reduce risk of joint contractures        |
| = 3 | Improve bladder and bowel function       |
| 5   | Improve bone density/strength            |
| 6   | Enjoy activities                         |
| 7   | Interaction with peers                   |
| 8   | Participation in activities              |
| 9   | Help child stand independently in future |
| 10  | Improve motor abilities (trunk control)  |
| 11  | Improve motor abilities (upper limbs)    |
| 12  | Help child walk in future                |
| 13  | Improve motor abilities (head control)   |
| 14  | Improve breathing                        |
| 15  | Help child use their vision              |
| 16  | Help child communicate                   |
| 17  | Reduce risk of fractures                 |



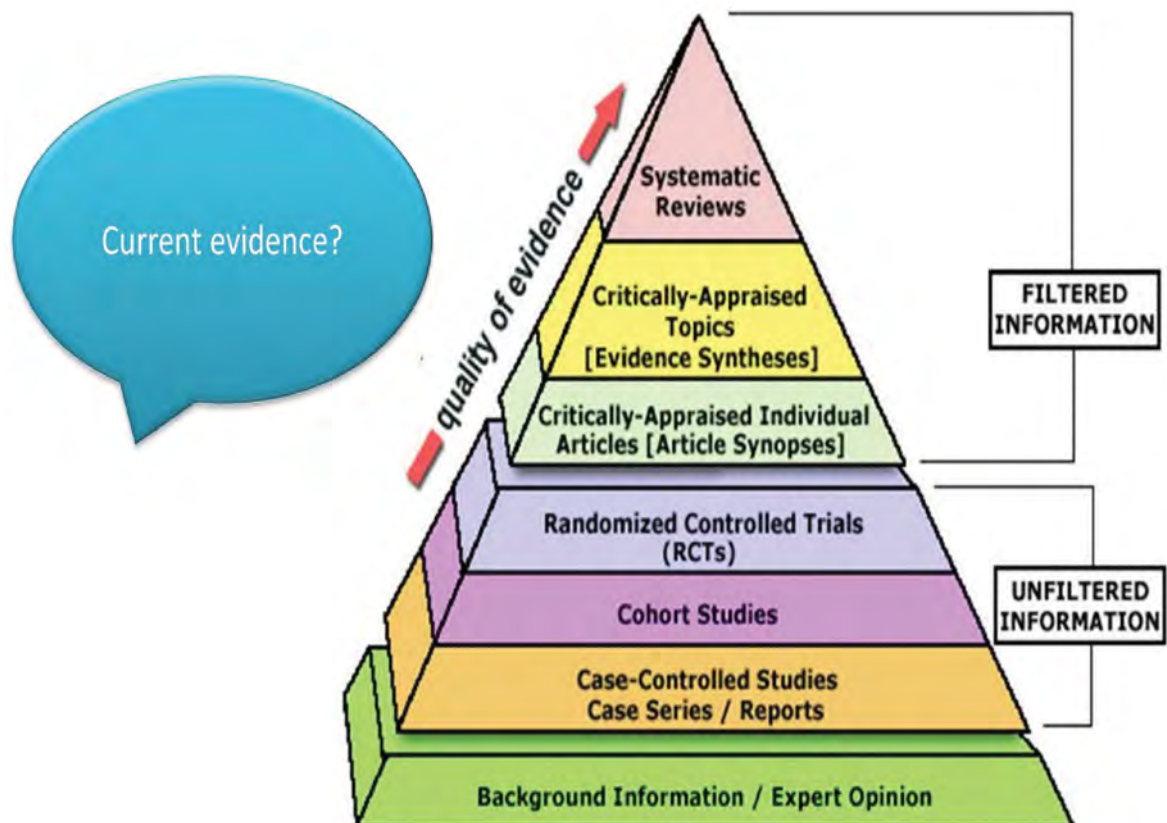


# understanding frames

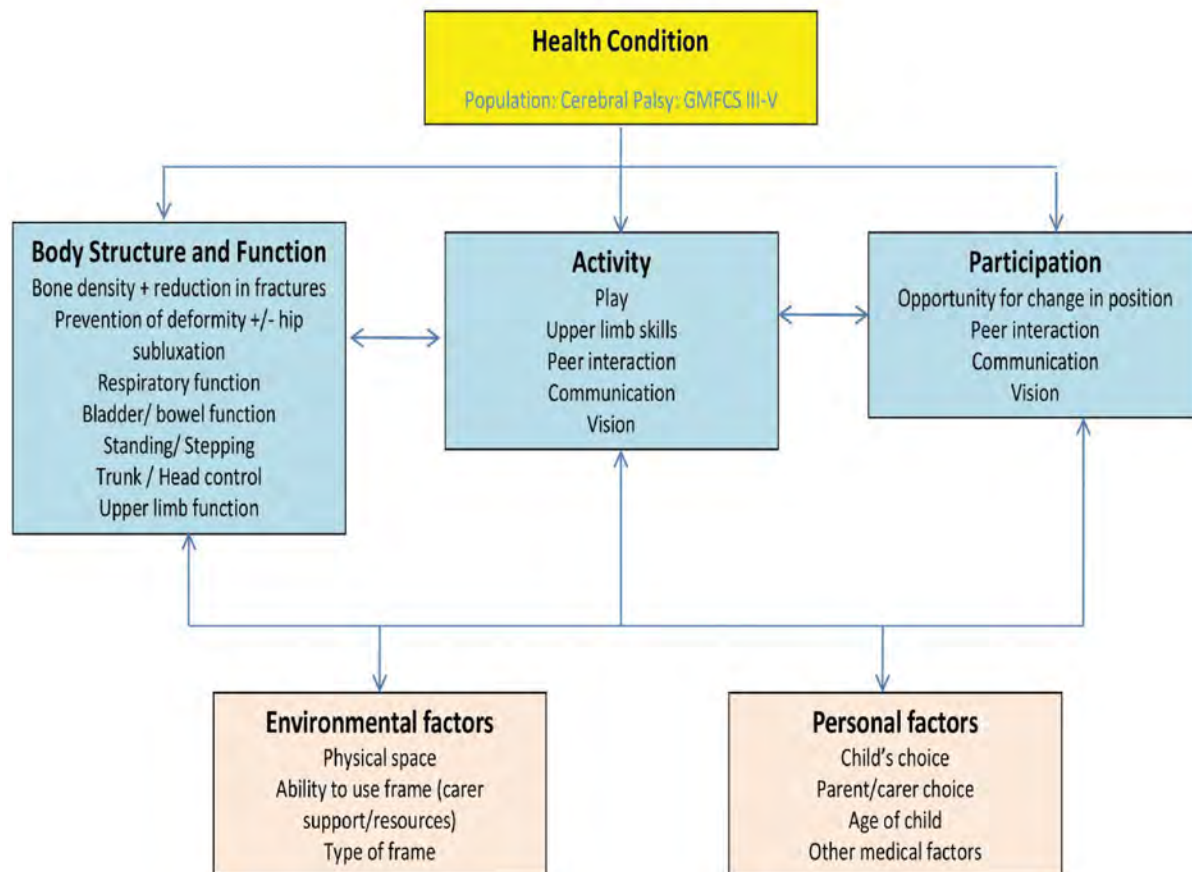
## Topics for today's discussion:

- What do you think of the benefits/ goals we have identified in the research so far? Which are most important to research? Are there any others?
- What is an acceptable period of not using a frame?
  - 6 weeks? A term? Longer? Never?
  - Delayed start for pre-school children?
    - Will this be different for different goals? i.e. if using for bowel function – how long?
- How do we ensure enough support to ensure a frame is used as planned?
  - Equipment/ training/ staff?

# understanding frames


# understanding frames





## Appendix 8 Survey 2: parents



**Understanding Frames Survey 2: Parents and carers**

**1. Introduction**

We invite you to take part in this questionnaire as part of the research study: 'Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?'

This study is being done by a research team [REDACTED] from Newcastle University. You are invited because you are a parent/carer of a child with cerebral palsy who may use a standing frame.

[You may have already taken part in this study by completing the first questionnaire, or attending a focus group. Your child may have participated in an interview.](#)  
*(Please click on the blue writing above if you would like to visit the study website and see summaries of the results so far.)*

We have used information from these earlier stages to think about research ideas. We would now like your opinion on these ideas, by completing this second questionnaire.

We want to gain as many people's views as possible. Some questions are very simple. Others may require a little more thought. Apart from confirming your consent, only 4 short questions require an answer, but please fill in as much as you can – your ideas are very important to us.

You may not directly benefit from this research. Taking part will help us plan future research, and hopefully will improve postural management for children with cerebral palsy. Your answers will be used to produce a report but individual comments will remain anonymous/confidential.

At the end of the questionnaire we will ask if you would like to be contacted regarding further research into standing frames. You do not need to give us any contact information if you do not wish to. Any contact information provided will be separated from your responses and kept securely by the research team. It will ONLY be used to contact you about further research.

Please ONLY input your contact details on the questionnaire if you agree to future contact from the research team and ONLY on the page indicated.

**Taking part is your choice and you can withdraw at any time.**

If you have questions about this project or if you have a research-related problem, you may contact:

[REDACTED]

By clicking on "I agree" to the questionnaire on the next page you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.

Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

## Understanding Frames Survey 2: Parents and carers

### 2. Consent

**\* 1. I am over 18 years of age and have read and understood the introduction page and I agree to completing this questionnaire.**

- ☐ I agree to continue and complete the questionnaire
- ☐ I do not wish to continue with the questionnaire

## Understanding Frames Survey 2: Parents and carers

### 3. About you

**2. You have been invited to do this questionnaire as you are a parent/carer of a child with cerebral palsy who may use or have used a standing frame.**

**Some parents and carers also work with children who have cerebral palsy and use standing frames. Please tick below to indicate which role this is:**

**(Please tick all that apply)**

- ☐ Classroom Support/Teacher
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy assistant or technical instructor
- ☐ Paediatrician in Neurodisability
- ☐ Paediatric Neurologist
- ☐ General Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ None of the above
- ☐ Other (please specify)

If you do have a professional role working with children with cerebral palsy who use standing frames, ***please continue to complete this survey from the point of view of a parent/carer.***

However, you would be welcome to click the website link below to complete our survey for professionals who work with children with cerebral palsy also.

[Click here for the link to the questionnaire for education or school workers.](#)

[Click here for the link to the questionnaire for health-care workers.](#)

3. Please tell us the first two letters or numbers at the start of your postcode.

## Understanding Frames Survey 2: Parents and carers

### 4. About your child

4. Please tell us the age (in years) of your child(ren) who uses (or has previously used) a standing frame.

If you have more than one child who uses a standing frame, please put the ages of all your children.

|         |                      |
|---------|----------------------|
| Child 1 | <input type="text"/> |
| Child 2 | <input type="text"/> |
| Child 3 | <input type="text"/> |
| Child 4 | <input type="text"/> |

If you have more than one child who uses a standing frame, please answer this questionnaire for the eldest child. If you would like you can repeat the questionnaire, answering for your other child(ren) afterwards.

### 5. My child has cerebral palsy

- ☐ Yes
- ☐ No
- ☐ I don't know

If no or I don't know, please write in the box below if your child has another named diagnosis.

### 6. My child attends a school/ nursery that is:

- ☐ Mainstream (state funded)
- ☐ Special school (state funded)
- ☐ Mainstream (private)
- ☐ Special school (private/other e.g. charity funding)
- ☐ Mixed mainstream and special school environment
- ☐ Other (please specify)



## Understanding Frames Survey 2: Parents and carers

### 5. Research about standing frame use for children with cerebral palsy.

Standing frames are used for children with cerebral palsy. They may improve how the body grows and develops, what the child can do standing up, and help the child to join in, but there has not been much research to prove that they do.

The purpose of the "Understanding Frames" project is to think about and design research studies about standing frames for children with cerebral palsy. We believe, as do many professionals, parents and the NHS research organisations, that further research is required to understand the benefits and disadvantages of using standing frames for children with cerebral palsy. However, this does not mean that all children and parents would agree. Therefore, we are asking you the important questions below.

So far we have talked to many people who use standing frames: including young people who use/d standing frames, parents, educational and health professionals. From these discussions we have thought about possible research studies.

Firstly, we would like to ask you some general questions about research into standing frames; then we will show you an example of a study and ask you some more specific questions.

## Understanding Frames Survey 2: Parents and carers

### 6. General questions regarding research about standing frames.

#### 7. Should standing frames be used for children with cerebral palsy?

- ☐ Yes
- ☐ No
- ☐ I don't know

Why?

#### \* 8. Do you think we should do further research about standing frames for children with cerebral palsy?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

If YES or I DON'T KNOW, please proceed to question 10, page 11.  
If NO, please proceed to question 9, page 10.



**Understanding Frames Survey 2: Parents and carers****7. General questions regarding research about standing frames.**

**\* 9. You have indicated in the question above that you are unsure OR do not believe that there is a need for research about the use of standing frames for children with cerebral palsy.**

The remainder of this questionnaire explains more about research, and asks questions about taking part in research. You would be welcome to continue with the questionnaire, and we would value your ideas about research, even if you don't believe in it yourself.

However, if you would rather finish the questionnaire now please indicate below.

- ☐ I would like to continue the questionnaire.
- ☐ I would like to stop the questionnaire now.

If you would like to continue the questionnaire, please turn to the next page and continue answering.  
If you would like to stop the questionnaire, please turn to page 24.

## Understanding Frames Survey 2: Parents and carers

### 8. General questions regarding research about standing frames.

**10. Would you allow your child to take part in a research study about standing frames if you and your child were given the right support?**

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

**11. Which age group of children with cerebral palsy would be most suitable for a standing frames research study?**  
(please tick all that apply)

- ☐ 0 – 5 years (pre-school and reception class)
- ☐ 6 – 10 years (primary school age)
- ☐ 11- 15 years (secondary school age)
- ☐ 16 – 18 years (sixth form or college students)
- ☐ No age groups are suitable for a standing frames research study

Please can you explain why you chose your answer above or comment if you have other ideas.

**\* 12. Does your child currently use a standing frame?**

- ☐ Yes
- ☐ No, they have never used a standing frame
- ☐ No, but they previously used a standing frame

If YES, please continue to question 13, page 13.  
If NO, please continue to question 16, page 14.

**Understanding Frames Survey 2: Parents and carers****9. For parents whose children currently use a standing frame**

**13. Would you be prepared to change how your child uses their standing frame for the purpose of a research study?**

- ☐ Yes
- ☐ No
- ☐ I don't know

**14. What is the longest possible time you would allow your child to have a break in using their standing frame for a research study?**

- ☐ Less than 2 weeks
- ☐ 2 weeks – 6 weeks
- ☐ 7 weeks - 12 weeks
- ☐ 13 weeks - 18 weeks
- ☐ 19 weeks - 24 weeks
- ☐ More than 24 weeks
- ☐ I would not let them stop using their standing frame
- ☐ I don't know

**15. If future research showed that standing frames were not useful (e.g., don't prevent contractures, don't increase enjoyment of participation in group activities with peers, etc.), would you be prepared for your child to stop using their standing frame?**

- ☐ Yes
- ☐ No
- ☐ I don't know

After answering this question, please turn to page 16.

### Understanding Frames Survey 2: Parents and carers

10. For parents whose children do not currently use a standing frame

16. You have indicated in the question above that your child does not currently use a standing frame, but has used one previously, OR has never used a standing frame.

The remainder of this questionnaire asks questions about standing frames research, which may require you think back to when your child was using a standing frame and/or imagine that your child uses a standing frame. You would be welcome to continue with the questionnaire, and we would value your ideas.

Please indicate below how you would like to proceed.

- ☐ I would like to finish the questionnaire
- ☐ I would like to stop the questionnaire now

If you would like to finish the questionnaire, please turn the page and continue answering from question 17.  
If you would like to stop the questionnaire, please turn to page 24.

### Understanding Frames Survey 2: Parents and carers

11. For parents whose children do not currently use a standing frame

17. If a standing frame was recommended for your child, how long would you be prepared to delay using it for a research study?

- ☐ Less than 2 weeks
- ☐ 2 weeks – 6 weeks
- ☐ 7 weeks - 12 weeks
- ☐ 13 weeks - 18 weeks
- ☐ 19 weeks - 24 weeks
- ☐ More than 24 weeks
- ☐ I wouldn't delay standing frame use
- ☐ I don't know



## Understanding Frames Survey 2: Parents and carers

### 12. Research study example: Do standing frames help children with cerebral palsy?

The example provided here is to show how a research study works in general terms. *This is not a study that is planned yet, but may help you to consider your answers to questions.* In the example, children would have access to a research physiotherapist to support their therapy programme.

We will be using your answers to the questions below to carefully design research studies.

#### **What is this study about?**

This study would see how children with cerebral palsy who use a standing frame benefit from using it compared to children with cerebral palsy who do not use a standing frame.

#### **How would my child take part?**

If you decided to take part then your child would be allocated by chance to one of two groups:

Group one: Physiotherapy programme for 12 weeks. For the first 6 weeks they would use standing frame for five days each week, then they would not use a standing frame for 6 weeks.

Group two: Physiotherapy programme for 12 weeks. For the first 6 weeks they would not use a standing frame, then for 6 weeks they would use a standing frame for five days each week.

#### **What would we have to do?**

- 1) Attend 3 assessments with a research physiotherapist. These may take 2-3 hours in total to complete, but your child will have time to rest.
- 2) Complete a diary of when your child uses their frame. (We will ask school staff to do this if your child stands in their frame in the classroom). This would take 5-10 minutes each day.
- 3) Complete another diary of your child's bowel habits and medications for 2 weeks whilst your child is using their standing frame and 2 weeks when they are not. This would take 5-10 minutes each day.
- 4) Agree for the research physiotherapist to visit your child, when they are using their frame, to measure their breathing, reported pain (or lack of), how they use their arms, and how they take part in the activities, in their standing frame and in supported sitting. This would take approximately one hour.

**Understanding Frames Survey 2: Parents and carers**

13. Is it possible to do this research?

18. If a standing frames research study was taking place, would you be comfortable with a health-worker asking you if you and your child would like to take part?

The health worker would explain the research study and what would be involved for you and your child. It would not mean that you and your child would have to take part. Taking part would be entirely your choice and if you decided not to take part your child's care would be exactly the same as they would normally be offered.

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

19. Would you be happy for your child to take part regardless of which group they were in?

- Group one: For the first 6 weeks they would use standing frame for five days each week, then they would not use a standing frame for 6 weeks.

- Group two: For the first 6 weeks they would not use a standing frame, then for 6 weeks they would use a standing frame for five days each week.

- ☐ Yes
- ☐ No
- ☐ I don't know

Please give a reason for your answer:

## Understanding Frames Survey 2: Parents and carers

### 14. Study assessments: Diary

#### 20. How easy would it be:

1 (It would be impossible)

2

3

4

5 (It would be easy)

to keep note of when your child uses their standing frame at home every day during the study (approx. 5-10 mins per day)?

☐
☐
☐
☐
☐

to keep a detailed diary of your child's bowel function, medications and pain daily for 2 weeks during the study (approx. 5-10 mins per day)?

☐
☐
☐
☐
☐

#### 21. How would you prefer to keep a diary of your child's standing frame use?

- ☐ Electronic (e.g., iPad, phone, computer)
- ☐ Hard copy (e.g., a book)
- ☐ Either electronic or hard copy
- ☐ I would not keep a diary
- ☐ Other (please specify)

#### 22. Please indicate if you would be prepared for you and your child to do any of these: (tick all that apply)

- ☐ Provide medical information for the purpose of research (it would remain anonymous)
- ☐ Complete questionnaires with your child about their participation and activities
- ☐ Allow your child to have detailed assessment by the research physiotherapist (measuring height, weight, and joints and movement skills)
- ☐ I would not agree to any of these.



## Understanding Frames Survey 2: Parents and carers

### 15. Study assessments

**23. In considering how we may design research studies, we need to consider the best location for assessments.**

**Please indicate below where you would agree for the assessments to take place at: (please tick all that apply)**

- ☐ School
- ☐ Home
- ☐ A clinic or centre where my child receives care usually
- ☐ A different clinic or hospital to where my child usually visits.

**Please can you explain why you chose your answer above:**

**24. During the research study example above, you and your child would need to attend up to 3 detailed assessments across the 12 weeks. The assessments could take up to 3 hours but we would ensure that your child would be given rest breaks and could stop at any time if they were tired. Travel expenses would be provided if needed.**

**How many of this type of assessment would you and your child would be able to do for a research study?**

- ☐ More than 3 assessments
- ☐ 3 assessments
- ☐ 2 assessments
- ☐ 1 assessment
- ☐ No assessments

**Please can you explain why you chose your answer above:**

**25. Would you agree to a research physiotherapist visiting your child for a shorter (maximum 1 hour) assessment (e.g., breathing, looking at the way they use their hands and asking them about pain) both in and out of their standing frame during the research study? You would be welcome to be there at the same time.**

- ☐ Yes
- ☐ No
- ☐ I don't know

**Please can you explain why you chose your answer above:**



## Understanding Frames Survey 2: Parents and carers

### 16. Reasons why people may not want to take part in research

In our discussions with people who use standing frames, they came up with a list of reasons (below) that might make a study difficult to do.

It may be possible to overcome some of these difficulties, but we need to know if any of them would stop you and your child taking part in this research.

**26. From the list of difficulties below, please tick any that would *stop you* allowing your child to participate in a research study:**  
(Please tick all that apply)

#### Practical reasons

- ☐ Children and young people with cerebral palsy are individual. This makes it impossible to research what standing frames do.
- ☐ Some benefits of standing frames cannot be measured (e.g., "feeling tall")
- ☐ There would not be enough space for the standing frame at home.
- ☐ There would not be enough space for the standing frame at school.
- ☐ None of these apply
- ☐ Other (please specify. E.g., I would not have time to take part, the school could not fit it into the daily routine, there are not enough school staff, there are not enough adults at home to help)

27. From the list of difficulties below, please tick any *that would stop you allowing your child to participate in a research study*:  
(Please tick all that apply)

**Family or personal choice**

- ☐ It is not right to stop standing frame treatment even for a short time for a research study.
- ☐ Standing frames are often recommended near to the time a child is diagnosed with cerebral palsy. It would be too much to ask parents to take part in research so soon after the diagnosis.
- ☐ I would be worried that stopping standing frame use for a research study would cause harm to my child that could not be reversed.
- ☐ I would feel guilty if I could not do everything I needed to do for the research study.
- ☐ It is an emotionally significant moment to see my child stand, it is more important to me than a research study.
- ☐ Taking part in a research study about standing frames may affect my child's quality of life negatively.
- ☐ My child's choice whether to use a standing frame is more important than a research study.
- ☐ None of these apply
- ☐ Other

**Understanding Frames Survey 2: Parents and carers****17. Thank you**

Thank you very much for taking the time to complete this questionnaire. Your ideas are very important to us. If you would like more information about this research, please contact us:



or go to our study webpage/Twitter where we will report on the progress of the study and upload results as they become available.

<https://research.ncl.ac.uk/understandingframes/>  
[@UnderstandFrame](#)

After this survey, we will be using your feedback to carefully design research studies.


The research study examples in this questionnaire are not final. We would like interested people to join us to make sure we are doing the best job possible.

**28. Please tick any of the below that you may be prepared to do:**

- ☐ Take part in email discussions regarding research designs
- ☐ Attend meetings to design research studies
- ☐ Other (please specify)



## Appendix 9 Survey 2: health professionals



# understanding frames

### Understanding Frames Survey 2: Health professionals

#### 1. Introduction

We invite you to take part in this questionnaire as part of the research study: 'Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?'

This study is being done by a research team led by Dr Jill Cadwgan from Newcastle University. You are invited because you are a health professional working with children with cerebral palsy who may use a standing frame.

You may have already taken part in this study by completing the first questionnaire, or attending a focus group.

*(Please click on the blue writing if you would like to visit our website and review the results summaries so far.)*

We have used information from these earlier stages to think about research ideas. We would now like your opinion on these ideas, by completing a questionnaire.

We want to gain as many people's views as possible. Some questions are very simple. Others may require a little more thought. Apart from confirming your consent, only 4 short questions require an answer, but please fill in as much as you can – your ideas are very important to us.

You may not directly benefit from this research. Your participation will inform future research, and hopefully will improve postural management for children with cerebral palsy. Your answers will be used to produce a report but individual comments will remain anonymous/confidential.

You do not need to give us any contact information. At the end of the questionnaire we will ask if you would like to be contacted regarding further research into standing frames. Any contact information provided will be separated from your responses and kept securely by the research team. It will ONLY be used to contact you about further research.

Please ONLY input your contact details on the questionnaire if you agree to future contact from the research team and ONLY on the page indicated.

Taking part is your choice and you can withdraw at any time.

If you have questions about this project or if you have a research-related problem, you may contact:

Dr Jill Cadwgan: [REDACTED]  
Jane Goodwin: [REDACTED]

By clicking on "I agree" to the questionnaire on the next page you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.

Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.





# understanding frames

## Understanding Frames Survey 2: Health professionals

### 2. Consent

\* 1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey.

- ☐ I agree to continue and complete the questionnaire
- ☐ I do not wish to continue with the questionnaire

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 3. About you

\* 2. My experience of using standing frames for children with cerebral palsy is based on my role as:

- ☐ Parent/carer
- ☐ Classroom Support/Teacher
- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy Assistant or Technical Instructor
- ☐ Paediatrician in Neurodisability
- ☐ Paediatric Neurologist
- ☐ General Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ Other (please specify)

*This questionnaire is designed for health professionals who work with children with cerebral palsy who use standing frames.*

There are alternative questionnaires for parents and educational professionals who work with children with cerebral palsy who use standing frames.

*Please click on the links below if you wish to complete any of the other questionnaires.*

[Click here for the link to the questionnaire for parents.](#)

[Click here for the link to the questionnaire for education professionals.](#)





# understanding frames

## Understanding Frames Survey 2: Health professionals

### 4. About you

#### 3. I work with:

- ☐ Children (any age from 0 to 18yrs) who use standing frames – but do not prescribe standing frames.
- ☐ Children (any age from 0 to 18yrs) and prescribe standing frames.

4. Please tell us the first two letters or numbers at the start of the postcode where you work. If you work across different locations, please use the location of your base employer.

#### 5. Please indicate your current working environments (please tick all that apply)

- ☐ In-patient (hospital)
- ☐ Outpatients (hospital based clinics)
- ☐ Child development or family centre clinic
- ☐ Community - home
- ☐ Community – **special** education centre (pre-school and/or school)
- ☐ Community – **mainstream** education centre (pre-school and/or school)
- ☐ Other (please specify)

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 5. Research regarding Standing Frames for children with cerebral palsy.

Standing frames are used for children with cerebral palsy. They may improve how the body grows and develops, what the child can do standing up, and help the child to join in, but there is little evidence that they do. There is also little evidence for whether they cause harm.


The purpose of the "Understanding Frames" project is to think about and design research studies about standing frames for children with cerebral palsy. We believe, as do many professionals, parents and the NHS research organisations, that further research is required to understand the benefits and disadvantages of using standing frames for children with cerebral palsy. However, this does not mean that all children, parents, health and education workers would agree. Therefore, we are asking you the important questions below.

So far we have explored research ideas through focus groups and interviews with people who have experience with standing frames. This has included children who use/d standing frames, parents, educational professionals, physiotherapists, occupational therapists, paediatricians, orthopaedic surgeons, and standing frame engineers.

If a study was to look at how the body grows and develops (body structure), outcomes such as joint range of movement, hip dislocation, preventing need for further surgery, or improvement in bone mineral density would need to be studied over several years and would need a large epidemiological population-based approach. This type of study is unlikely to be feasible or funded.

Therefore, we propose short- to medium-term studies looking at the more immediate benefits that we might see in children with cerebral palsy, such as activity, participation, bowel function, respiratory function, pain, communication, and upper limb function. These studies would need to be in a controlled environment with adequate support to ensure delivery of the intervention. The comparison group would either be involved in a cross-over design or a delayed start design.

Firstly we want to ask you some general questions about research into standing frames; then we will show you a study example and ask you some more specific questions.

# understanding frames

**Understanding Frames Survey 2: Health professionals**

**6. Importance of a research study**

6. Do you think standing frames should be used for children with cerebral palsy who are unable to stand independently (GMFCS III-V)?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

7. Do you personally believe that standing frames are clinically effective?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

\* 8. Do you think that further research into the use of standing frames for children with cerebral palsy is necessary?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

If YES or I DON'T KNOW, please proceed to question 10, page 10.  
If NO, please proceed to question 9, page 9.



# understanding frames

## Understanding Frames Survey 2: Health professionals

### 7. General questions regarding research about standing frames.

- \* 9. You have indicated in the question above that you are unsure OR do not believe that there is a need for research about the use of standing frames for children with cerebral palsy.

The remainder of this questionnaire explains more about research, and asks questions about taking part in research. You would be welcome to continue with the questionnaire, and we would value your ideas about research, even if you don't believe in it yourself.

However, if you would rather finish the questionnaire now please indicate below.

- ☐ I would like to continue the questionnaire.
- ☐ I would like to stop the questionnaire now.

If you would like to continue the questionnaire, please turn to the next page and continue answering.

If you would like to stop the questionnaire, please turn to page 22.

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 8. General questions regarding research about standing frames.

10. Would you agree to take part in a research study which might require you to change your practice during the research?

- ☐ Yes
- ☐ No
- ☐ I don't know

11. If future well designed research provided good quality evidence that standing frames were not beneficial, would you agree for children with cerebral palsy to stop using them?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:



12. Which age group of children with cerebral palsy do you think would be most suitable for a standing frames research study?

(Please tick all that apply)

- ☐ 0 – 5 years (pre-school and reception class)
- ☐ 6 – 10 years (primary school age)
- ☐ 11– 15 years (secondary school age)
- ☐ 16 – 18 years (sixth form or college students)
- ☐ No age groups are suitable for a standing frames research study

Please can you explain why you chose your answer above:

13. Many therapeutic interventions that are used for children with cerebral palsy have little research evidence. Please indicate the extent to which you agree or disagree with the statement below:

|   | 1 (Strongly disagree) | 2                     | 3                     | 4                     | 5 (Strongly agree)    |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| A research study of standing frames could provide valuable information about how to investigate other similar interventions with little evidence. | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 9. Research study example

The example provided here is to show how a research study works in general terms. This is not a study that is planned yet, but may help you to consider your answers to questions.

We will be using your answers to the questions below to carefully design research studies; with interested children, parents and experts from across the UK who work with children with cerebral palsy.

#### *Aims and Hypotheses*

##### Aims:

- To determine if standing frames can improve participation in children with cerebral palsy.
- To determine if standing frames can improve aspects of body function in children with cerebral palsy.

##### Hypotheses

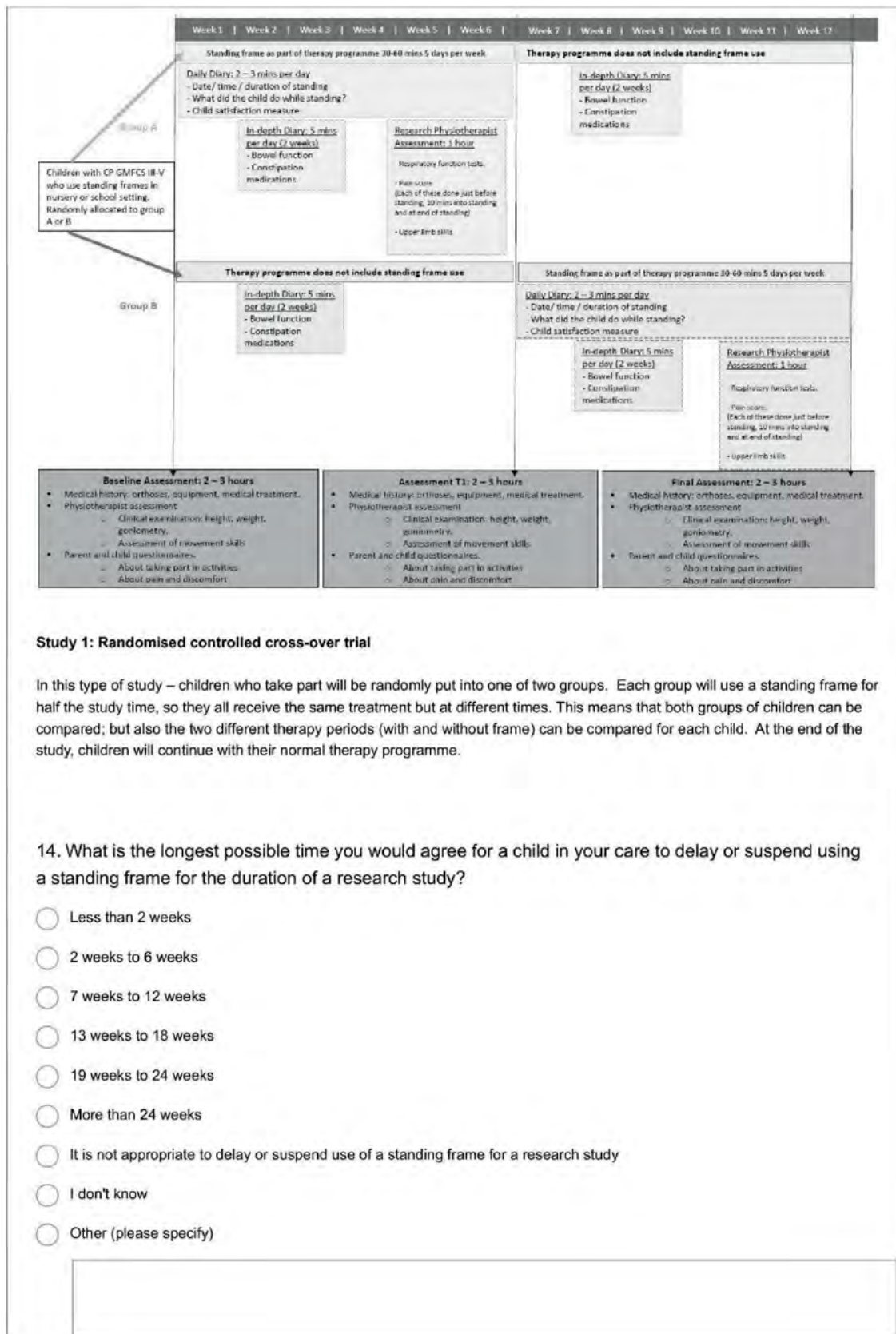
- Standing frames can increase participation in children with cerebral palsy. For example:
  - o Joining in with activities in school or home
  - o Developing relationships with other children
- They may also provide some improvement in body function including:
  - o Gross motor function
  - o Bowel function
  - o Respiratory Function
  - o Upper limb function
  - o Reduce pain


In this study, the possible benefits or disadvantages of using a standing frame can be seen in a short period of time.

All children would receive their usual treatments but would also have access to a research physiotherapist to support their standing frame use and carry out assessments for the research study. The children may have more detailed assessment by the research physiotherapist than they would normally have in routine care, which will take time, but should be beneficial to their overall care.

The flowchart below explains how a child would be involved in the study. If you are having trouble viewing it, [please click here to view it in PDF form.](#)







# understanding frames

## Understanding Frames Survey 2: Health professionals

10. Is it possible to do this research?

15. If there was a standing frame research study in your place of work, who would be appropriate to recruit participants? Please select any that apply:

- ☐ Physiotherapist
- ☐ Occupational Therapist
- ☐ Therapy Assistant or Technical Instructor
- ☐ Paediatrician
- ☐ Orthopaedic Surgeon
- ☐ I don't know
- ☐ Other (please specify)

16. In principle, would you be willing to recruit participants to this study?  
(This would mean identifying children who may be able to take part, discussing the study with them and their parents, and contacting the research team.)

☐ Yes  
☐ No  
☐ I don't know

Please can you explain why you chose your answer above:

17. In reality, could you recruit participants to this study?

(This would mean identifying children who may be able to take part; discussing the study with them and their parents and contacting the research team.)

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

18. Would you have time to recruit participants to a research study in your current role?

- ☐ Yes
- ☐ No
- ☐ I don't know

\* 19. Do you have relevant clinical training which allows you to consent participants to a research study?  
E.g. Good Clinical Practice (GCP) training

- ☐ Yes
- ☐ No
- ☐ I don't know

# understanding frames




## Understanding Frames Survey 2: Health professionals

11. Is it possible to do this research?

20. Would you be prepared to do relevant training e.g. Good Clinical Practice (GCP) training in order to consent children to a standing frame research study?

- ☐ Yes
- ☐ No
- ☐ I don't know

If YES, please continue to question 21, page 19.  
If NO or I DON'T KNOW, please turn to the next page and  
continue answering from question 20.



# understanding frames

Understanding Frames Survey 2: Health professionals

12. Is it possible to do this research?

21. Would you be prepared for a research physiotherapist to be involved in the child's care for the duration of the study? This would mean they are involved in discussion about the child's therapy goals with relation to the use of standing frames, and carrying out assessments for outcome measures.

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

# understanding frames



## Understanding Frames Survey 2: Health professionals

### 13. Acceptability of research

Before designing this questionnaire, we consulted standing frame users including children who use/d standing frames, parents, educational professionals, physiotherapists, occupational therapists, paediatricians, orthopaedic surgeons, and standing frame engineers.

They came up with a list (below) of reasons that might make a study difficult to do. It may be possible to overcome some of these difficulties, but we need to know which are the most important.

22. From the list of difficulties below, please tick any *that would stop you recruiting children for a research study about standing frames*:

(please tick all that apply)

Practical reasons

- ☐ A research study would be too resource intensive to be feasible.
- ☐ A research study would be too labour intensive to be feasible.
- ☐ Children with CP are individual. It is impossible to research the impact of standing frames.
- ☐ Some benefits of standing frames cannot be measured (e.g., "feeling tall")
- ☐ It will be too difficult to get children and parents to participate in a research study.
- ☐ It will be too difficult to get professionals to participate in a research study.
- ☐ I would not have the support in my workplace to take part in a research study.
- ☐ Other (please specify)



23. From the list of difficulties below, please tick *anythat would stop you recruiting children for a research study about standing frames*:

(please tick all that apply)


Ethical or personal choice reasons:

- ☐ It is not right to withdraw standing frame treatment for a research study.
- ☐ I would be worried that stopping standing frame use for a research study would cause harm to children that could not be reversed.
- ☐ Participating in a research study about standing frames may affect the child's quality of life negatively.
- ☐ The child's choice, rather than a research study should dictate their standing frame use.
- ☐ Other (please specify)

24. If a multi-centre research study was to take place, I would want children in my region to have the opportunity to take part in the research:

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:



# understanding frames

**Understanding Frames Survey 2: Health professionals**

14. Thank you

Thank you very much for taking the time to complete this questionnaire. Your contribution is highly valued. If you would like more information regarding this research, please contact us:

Dr Jill Cadwgan: [REDACTED]

Jane Goodwin: [REDACTED]

or go to our study webpage/Twitter where we will report on the progress of the study and upload results as they become available.

<https://research.ncl.ac.uk/understandingframes/>  
[@UnderstandFrame](#)

The next stage of the Understanding Frames project is to design robust studies to examine standing frame use in children with cerebral palsy. We would like interested people to join us to make sure we are doing the best job possible.

25. Please tick any of the below that you may be prepared to do:

☐ Take part in email discussions regarding research designs

☐ Attend meetings to design research studies

☐ Become a participating site in a multi-centre study

☐ Other (please specify)



26. If you have ticked any of the above or are interested in receiving any further information, please put your contact details below:

|               |                      |
|---------------|----------------------|
| Name          | <input type="text"/> |
| Address       | <input type="text"/> |
| Address 2     | <input type="text"/> |
| City/Town     | <input type="text"/> |
| Postal Code   | <input type="text"/> |
| Country       | <input type="text"/> |
| Email Address | <input type="text"/> |
| Phone Number  | <input type="text"/> |

27. As you have completed the survey, you are entitled to a £10 gift voucher. Please insert a personal code word below. To claim this voucher, please contact Jane Goodwin: XXXXXXXXXX

*You will need to remember your code word in order to collect the voucher.*


If you have an alternative role working with or caring for children with cerebral palsy who use standing frames, we would be delighted if you completed our other survey/s:

[Click here for the link to the questionnaire for parents.](#)

[Click here for the link to the questionnaire for education professionals.](#)



# Appendix 10 Survey 2: education professionals



## understanding frames

**Understanding Frames Survey 2: Educational professionals**

**1. Introduction**

We invite you to take part in this questionnaire as part of the research study: 'Standing frames as postural management for children with spasticity, what is the acceptability of a trial to assess the efficacy of standing frames?' [REDACTED]

This study is being done by a research team led by Dr Jill Cadwgan from Newcastle University. You are invited because you are an education professional who works with children with cerebral palsy who may use a standing frame.

You may have already taken part in this study by completing the first questionnaire, or attending a focus group. We have used information from these earlier stages to think about research ideas. We would now like your opinion on these ideas, by completing a second questionnaire. *(If you would like to visit the study website and review our findings so far, click on the blue writing above.)*

We want as many people's views as possible. Some questions are very simple. Others may require a little more thought. Apart from confirming your consent, only 3 short questions require an answer, but please fill in as much as you can – your ideas are very important to us.

You may not directly benefit from this research. Taking part will help us plan future research, and hopefully will improve postural management for children with cerebral palsy. Your answers will be used to produce a report but individual comments will remain anonymous/confidential.


At the end of the questionnaire we will ask if you would like to be contacted regarding further research into standing frames. You do not need to give us any contact information if you do not wish to. Any contact information provided will be separated from your questionnaire responses and kept securely by the research team. It will ONLY be used to contact you about further research.

Please ONLY input your contact details on the questionnaire if you agree to future contact from the research team and ONLY on the page indicated.

Taking part is your choice and you can withdraw at any time.

If you have questions about this project or if you have a research-related problem, you may [REDACTED]

Dr Jill Cadwgan: [REDACTED]

  
By clicking on "I agree" to the questionnaire on the next page you are indicating that you are at least 18 years old, have read and understood this consent form and agree to participate in this research study.

Understanding Frames is an independent research study funded by the National Institute for Health Research (NIHR) under its Health Technology Assessment (HTA) Programme. The views expressed here are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.




# understanding frames

## Understanding Frames Survey 2: Educational professionals

### 2. Consent

\* 1. I am over 18 years of age and have read and understood the consent paragraph above regarding this survey.

- ☐ I agree to continue and complete the questionnaire
- ☐ I do not wish to continue with the questionnaire



# understanding frames

Understanding Frames Survey 2: Educational professionals

3. About you


\* 2. My experience of using standing frames for children with cerebral palsy is based on my role as:

☐ Classroom Support/Teacher  
☐ Health professional  
☐ Parent  
☐ Other (please specify)

*This questionnaire is designed for educational professionals who work with children with cerebral palsy who use standing frames.*

There are alternative questionnaires for parents and for healthcare professionals who work with children with cerebral palsy who use standing frames.

[Click here for the link to the questionnaire for parents.](#)  
[Click here for the link to the questionnaire for health-care professionals.](#)



# understanding frames

Understanding Frames Survey 2: Educational professionals

4. About you

3. Please tell us first two letters or numbers at the start of the postcode where you work. If you work across different locations, please use the location of your base employer.

4. I work with children in the following age groups:  
(Please tick all that apply)

☐ Nursery / Preschool

☐ Primary school

☐ Secondary school

☐ Post 16 / College

5. I work in a school/ nursery that is:

☐ Mainstream (state funded)

☐ Special school (state funded)

☐ Mainstream (private)

☐ Special school (private/other e.g. charity funding)

☐ Mainstream school with additional resource for SEND

☐ Other (please specify)



# understanding frames



## Understanding Frames Survey 2: Educational professionals

### 5. Research about standing frames for children with cerebral palsy

Standing frames are used for children with cerebral palsy. They may improve how the body grows and develops, what the child can do standing up, and help the child to join in, but there has not been much previous research to prove that they do.

The purpose of the "Understanding Frames" project is to think about and design research studies about standing frames for children with cerebral palsy. We believe, as do many professionals, parents and the NHS research organisations, that further research is required to understand the benefits and disadvantages of using standing frames for children with cerebral palsy. However, this does not mean that all children, parents and education workers would agree. Therefore, we are asking you the important questions below.


So far we have talked to many people who use standing frames: including children who use/d standing frames, parents, educational and health professionals. From these discussions we have thought about possible research studies.

If a study was to look at how the body grows and develops (for example: maintaining the range of movement at joints and muscles, preventing hip dislocation, preventing need for surgery, or making bones stronger) then the research would need to take several years and would need many hundreds of young people to take part. This type of study may not be possible; for example, there may be difficulties obtaining funding or recruiting participants.

Shorter term studies looking at the more immediate things that we might see in children with cerebral palsy, such as taking part in activities and how the body works (bowel function, breathing, pain, and using their arms) are more likely to be possible. These studies would need to be carefully organised with support to make sure that all the children and families in the study get the planned treatment.

Firstly we want to ask you some general questions about research into standing frames; then we will show you a study example and ask you some more specific questions.



# understanding frames

**Understanding Frames Survey 2: Educational professionals**

**6. General questions regarding research about standing frames.**

6. Should standing frames be used for children with cerebral palsy who are unable to stand independently?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

\* 7. Do you think further research is needed about standing frames for children with cerebral palsy?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

If NO or I DON'T KNOW, please proceed to QUESTION 8.

If YES, please proceed to QUESTION 9, SECTION 8.



# understanding frames

## Understanding Frames Survey 2: Educational professionals

### 7. General questions regarding research about standing frames.

- \* 8. You have indicated in the question above that you are unsure OR do not believe that there is a need for research about the use of standing frames for children with cerebral palsy.


The remainder of this questionnaire explains more about research, and asks questions about taking part in research. You would be welcome to continue with the questionnaire, and we would value your ideas about research, even if you don't believe in it yourself.

However, if you would rather finish the questionnaire now please indicate below.

- ☐ I would like to continue the questionnaire.
- ☐ I would like to stop the questionnaire now.

If you would like to continue the questionnaire, please turn to the next page and keep answering.

If you would like to stop the questionnaire, please turn to SECTION 12.

# understanding frames

**Understanding Frames Survey 2: Educational professionals**

**8. General questions regarding research about standing frames.**

9. Would you be comfortable with changing how a child uses a standing frame for a research study?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

10. If future research showed that standing frames were not useful (e.g., don't prevent contractures, don't increase enjoyment of participation in group activities with peers, etc.), would you be comfortable with your students stopping using them?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

11. Which age group of children with cerebral palsy would be most suitable for a standing frames research study?

- ☐ 0 – 5 years (pre-school and reception class)
- ☐ 6 – 10 years (primary school age)
- ☐ 11- 15 years (secondary school age)
- ☐ 16 – 18 years (sixth form or college students)
- ☐ No age groups are suitable for a standing frames research study

Please can you explain why you chose your answer above:



# understanding frames

## Understanding Frames Survey 2: Educational professionals

### 9. Research study example: Do standing frames help children with cerebral palsy?

The example provided here is to show how a research study works in general terms. This is not a study that is planned yet, but may help you to consider your answers to questions.

We will be using your answers to the questions below to carefully design research studies with interested children, parents and experts from across the UK who work with children with cerebral palsy.

In the example, children would have access to a research physiotherapist to support their therapy programme. The children would have more detailed assessments by the research physiotherapist than they would normally have in routine care, which would take time, but it may help you to understand their abilities more.

#### What is this study about?

This study would see how children with cerebral palsy who use a standing benefit from using it compared to children with cerebral palsy who do not use a standing frame.

#### How would a child will take part?

With parent consent a child would be allocated by chance to one of two groups:

Group one: Physiotherapy programme for 12 weeks. For the first 6 weeks the child would use a standing frame for five days each week (at school or home), then they would not use standing frame for 6 weeks.

Group two: Physiotherapy programme for 12 weeks. For the first 6 weeks the child would not use a standing frame, then they would use a standing frame for five days each week (at school or home).


#### What would we have to do?

- 1) Complete a daily diary to record when the child uses their frame at school. This would take 5-10 minutes each day.
- 2) Jointly with parents complete a more detailed diary of a child's bowel habits and medications for 2 weeks whilst the child is using their standing frame and when they are not (if this is relevant during the school day). This would take 5-10 minutes each day.
- 3) When the child is using their standing frame a research physiotherapist will visit them on one occasion, to measure their breathing, reported pain, how they use their arms, and the way they take part in the activities they choose both in their standing frame and in a supported sitting position. This would take approximately one hour, and may occur at school.

#### What would happen at the end of the study?

At the end of the study the child would return to usual care.





# understanding frames

Understanding Frames Survey 2: Educational professionals

10. Is it possible to do this research?

12. If children at your school were participating in a study, would you be happy for them to take part regardless of which group they were in?

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

13. If more than one child in your classroom was in a study, would it matter if they were in different groups? (i.e. one child using a standing frame and one child not using a standing frame at the same time)

☐ Yes

☐ No

☐ I don't know

Please can you explain why you chose your answer above:

14. Would you agree to a research physiotherapist visiting a child at school for an assessment (e.g., to evaluate the child's breathing, to consider their hand function, or to consider if they are in pain) for a maximum of 1 hour during the research study?

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above:

15.

**1 (It would be impossible)**

**2**

**3**

**4**

**5 (It would be easy)**

How easy would it be to keep a daily diary of when a child at your school uses their standing frame (5-10 mins per day)?

☐
☐
☐
☐
☐

If a child needed to keep a more detailed diary of their bowel function, medications, and pain could you fill this in for the time they are at school? (5-10 mins per day)

☐
☐
☐
☐
☐

16. How would you prefer to keep a diary for a child at your school's standing frame use?

- ☐ Electronic (e.g., iPad, phone, computer)
- ☐ Hard copy (e.g., a book)
- ☐ Either hard copy or electronic
- ☐ I would not keep a diary
- ☐ Other (please specify)

17. Would you agree to work with a research physiotherapist? This would involve having a research physiotherapist come into school to assess and support children participating in the study.

- ☐ Yes
- ☐ No
- ☐ I don't know

Please can you explain why you chose your answer above if possible?





# understanding frames

## Understanding Frames Survey 2: Educational professionals

### 11. Reasons why people may not want to take part in research

Before designing this questionnaire, we consulted standing frame users including young people who use/d standing frames, parents, educational professionals, physiotherapists, occupational therapists, paediatricians, orthopaedic surgeons, and standing frame engineers.

They came up with a list (below) of reasons that might make a study difficult to do. It may be possible to overcome some of these difficulties, but we need to know which the biggest ones to consider are.

18. From the list of difficulties below, please tick *anythat would stop you participating in a research study*:  
(please tick all that apply)

#### Practical reasons

- ☐ Children and young people with cerebral palsy are individual. This makes it impossible to research what standing frames do.
- ☐ Some benefits of standing frames cannot be measured (e.g., "feeling tall")
- ☐ There would not be enough space for children's standing frames at school.
- ☐ None of these apply
- ☐ Other (please specify: E.g., I would not have time to take part, the school could not fit it into the daily routine, there are not enough school staff)

19. From the list of difficulties below, please tick any *that would stop you participating in a research study*:  
(please tick all that apply)

Personal choice reasons

- ☐ It is not right to stop standing frame treatment for a research study.
- ☐ I would be worried that stopping standing frame use for a research study would cause harm to children that could not be reversed.
- ☐ I would feel guilty if I could not do everything I needed to do for the research study.
- ☐ Participating in a research study about standing frames may affect children's quality of life negatively.
- ☐ Children's choice should dictate their standing frame use rather than a research study.
- ☐ None of these apply
- ☐ Other (please specify)



# understanding frames

## Understanding Frames Survey 2: Educational professionals

### 12. Thank you

**Thank you very much for taking the time to complete this questionnaire. Your ideas are very important to us. If you would like more information about this research, please contact us:**



**or go to our study webpage/Twitter where we will report on the progress of the study and upload results as they become available.**

**<https://research.ncl.ac.uk/understandingframes/>**  
**[@UnderstandFrame](#)**

**After this survey, we will be using your feedback to carefully design research studies.**

**The research study examples in this questionnaire are not final. We would like interested people to join us to make sure we are doing the best job possible.**

**20. Please tick any of the below that you may be prepared to do:**

- ☐ Take part in email discussions regarding research designs
- ☐ Attend meetings to design research studies
- ☐ Other (please specify)





A decorative graphic consisting of numerous thin, parallel green lines that curve from the left side of the page towards the right, creating a sense of movement and depth.

EME  
HS&DR  
HTA  
PGfAR  
PHR

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